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A Phenomenological Investigation of Music Therapists' Experiences when Working With Actively Dying Hospice Patients: an Analysis of Words, Mandalas, and Music

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A PHENOMENOLOGICAL INVESTIGATION OF MUSIC THERAPISTS' EXPERIENCES WHEN WORKING WITH ACTIVELY DYING HOSPICE PATIENTS: AN ANALYSIS OF WORDS, MANDALAS, AND MUSIC

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DEDICATION

This research study is dedicated to all of the hospice patients and families who have taught me so much about life and death, relationships, and decision-making. It has truly been an honor to share your precious time, and while I was trying to my best to support you, you in turn have helped me come into a fuller understanding of myself. Thank you.

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Thank you to the cohort that I started this journey with and supported me along my educational journey. I continue to treasure the friendships we now share.

And finally, thank you to my dear, sweet children Brandon, Keller, and Milla. You helped me play and find joy amidst the stress around planning and deadlines. I hope you read this someday and discover something new about your mom.

SUMMARY

A PHENOMENOLOGICAL INVESTIGATION OF MUSIC THERAPISTS' EXPERIENCES WHEN WORKING WITH ACTIVELY DYING HOSPICE PATIENTS: AN ANALYSIS OF WORDS, MANDALAS, AND MUSIC

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SUMMARY:

This phenomenological study explored the lived experiences of three music therapists when working with actively dying hospice patients. The participants spoke of their experiences, drew mandalas, and improvised music. Through the lens of Interpretive Phenomenological Analysis the interview transcripts were coded two main themes emerged: clinical experiences and personal experiences. Subthemes under clinical experiences included use of ongoing assessment, clinical reasoning, clinical use of music to meet patient needs, roles as music therapist, facing challenges in the work, and working with patients' spirituality. Subthemes under personal experiences included awareness of needs for self-care, physical and sensory experiences, emotions and new awareness from the work, a deepened understanding of death, and the work as spiritual on a personal level. Spiritual and emotional experiences were present on both clinical and personal experiences. The mandalas and music improvisation served to help the participants reflect more on their personal experiences.

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Chapter 1: Introduction

The greatest mystery in life is not life itself, but death.

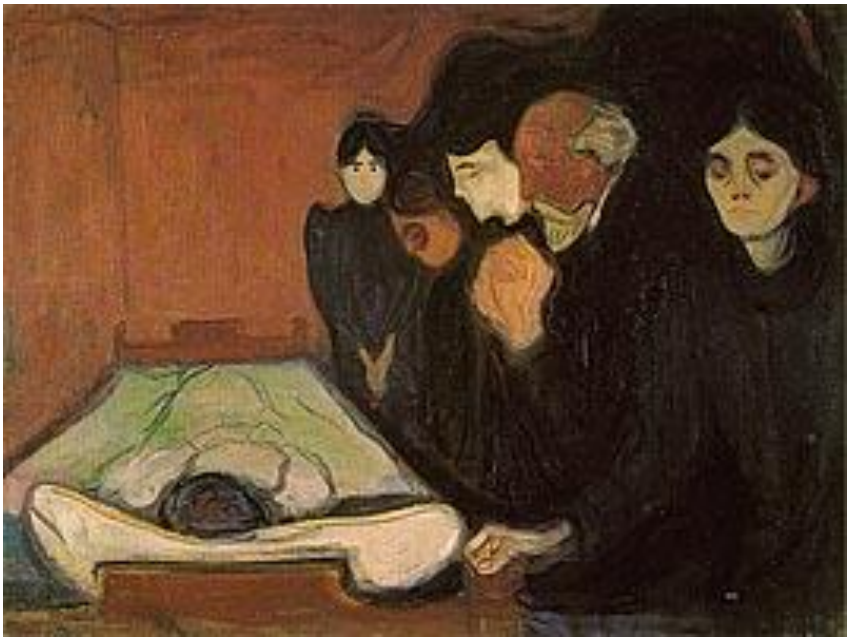
-Rajneesh

"What is death?" and "What happens after death?" have been existential questions that have persistently crossed the minds of humankind for centuries. The mysteriousness of death is often anxiety-provoking and certainly in American culture the topic is often eschewed (Colaizzi, 2002; Yalom, 1980). As an experience most people do not want to talk about, it is easy to live with death-avoidance (Gawande, 2014). The fact is all people die and there are unique needs of care in the dying process. With the advent of hospice philosophy and recognition by reimbursement sources such as Medicare, more and more health care professionals are choosing to work in hospice and palliative care (Lammers, Barbour, & Duggan, 2003), including music therapists. This study seeks to illuminate an understanding the music therapist's experience when working with actively dying hospice patients.

While death and being present with the dying are not easily talked about, depictions of these experiences are found in creative expression in art and music. Michaelangelo's *Pieta* is one of these examples, and is a famous sculpture of Mary's Lamentation of Jesus Christ.

Picture 1: Michaelangelo's *Pieta* (http://www.italianrenaissance.org/michelangelos-pieta/)

It is said the sculpture shows Mary's deep grief while she tenderly holds her dead son, and her calm facial expression exudes both resignation and acceptance. With an extended hand she invites others to grieve with her (Michaelangelo's Pieta, 2016). Another work, a painting by Edvard Munch called *By the Deathbed,* shows the sorrow and grief in faces of those gathered at the bedside. Perhaps inspired by the deaths of his mother and sister of tuberculosis when he was a child, as well as the deaths of his father, brother, and another sister just a few years later, death and sickness are a recurrent theme in all of his works. In this painting the mourners appear in deep sorrow, and it is difficult to discern the boundaries of their bodies, as if the grief envelops them together (By the Deathbed, n.d.).



Picture 2: Munch's *By the Deathbed* (http://www.edvardmunch.org/by-the-death-bed.jsp)

The experience of being present to death is also found in music, such as in Chopin's famous *Funeral March* (third movement of Piano Sonata in B Flat Minor). The piece opens with low, alternating chords and a simple, haunting melody. The rhythm drags the listener at *largo* tempo along the march through the bass notes. With a change to the relative major key of G-flat major, the B section contains open arpeggiated chords to harmonically support a simple and sweet step-wise melody in the upper register. The melody sounds of happier times when the loved one was still living. Just as this section peacefully enters, it concludes, and the A section returns with the reality of the purpose of the day, which is the procession of the body to grave. The reader may wish to hear this piece by using the following link: https://www.youtube.com/watch?v=3yh2InVsFag.

Another piece, Bach's *Come Sweet Death*, also depicts the death experience in music. With a slow and sorrowful chord progression in the key of C minor, the listener hears a peaceful lament that builds into rich, full harmonies that cry of both pain and joy, a paradox that often accompanies feelings around death as many believe death to be a loss but also a relief from suffering (https://www.youtube.com/watch?v=Xje4OYalB5Q). Two other pieces, Berlioz's *Symphony Fantastique* and Lizts's *Totentanz,* incorporate a medieval chant for departed souls called *Dies Irae* ("Day of Wrath"). Many other western classical pieces are about death, such as Strauss's *Death and Transfiguration* and Mahler's *Kindentotenlieder*. In addition, death is often the ultimate price the opera character plays in plots of love and deception, as in Verdi's *Rigoletto*.

What does a discussion on death in art and music have to do with the present study? Being at the bedside of a dying person is sacred and profound and can be difficult to explain to others, even other music therapists who do not work in hospice. This study explored the lived experiences of music therapists who have worked with actively dying patients (patients experiencing an active process of the body shutting down and may be minutes, hours or days from death), and drawing mandalas and making music were incorporated to express these experiences. My initial supposition was that more could be understood about these experiences through creative expression. I believed that art and music could reveal more than words could express.

Evidence-Based Practice

Music therapists provide music therapy services that are informed by evidence toward efficacy, and there are several types of evidence that should be taken into consideration. Abrams (2010) identified the need for an integral understanding of evidence to inform music therapy practice. He defined evidence as

> Indications, manifestations, and/or signs that serve as sufficient grounds for beliefs, judgments, formation of conclusions, or proof about a given phenomenon, by bearing witness to, and making plain or clear, certain aspects of that phenomenon. (p. 352)

Sources of evidence include objective evidence, which results from what is often referred to as data-based research (Abrams, 2010). A music therapist may ascribe to evidence-based practice by examining published quantitative research findings and implementing a treatment plan using protocols that were found to have significant effects (Bruscia, 2014).

Another type of evidence a music therapist may integrate into practice is subjective evidence, which includes qualitative research, case studies, and training and work experience (Abrams, 2010). Phenomenology is one type of qualitative research methodology that has been used to examine aspects of the therapeutic process, resulting in evidence intended to promote expansion of the breadth and depth of the music therapist's knowledge and understanding. Evidence within phenomenological studies serves to *enlighten* the music therapist. Bruscia (1998) writes

> An enlightening study is one that helps the researcher, participants, and/or audience to develop an expanded consciousness, new insights and understandings, more varied and informed perspectives, enlarged constructions, more vivid values, more deeply felt experiences, clearer connections, greater creativity, more significant meanings, and greater appreciation. (p. 193)

The importance of art in research is highlighted in Aigen's (2015) critique of evidence-based practice. Art within research can help the researcher come into a deeper understanding of the data, as well as serve as an expression of the data, thus helping the reader better understand the results and adding to the body of evidence from which to draw from. Utilizing art within the research process

> …addresses complex and often subtle interactions and…it provides an image of those interactions in ways that make them noticeable. In a sense, arts-based research is a heuristic through which we deepen and make more complex our understanding of some aspect of the world. (Barone & Eisner, 2012 in Viega & Forinash, 2016, p. 491)

The roles of art within research range from adjunctive to the method (part of collecting and/or analyzing data), primary to the method (integral to every step of the method), primary to the methodology (essential to the theoretical constructs of the study), or a radical event in the study (promoting social and political change). This study supports the use of art as an adjunctive method in research because of its supportive role in data collection.

Phenomenology

This study sought to understand a human experience, which is the core aim of phenomenological philosophy and research. Through phenomenology a deeper understanding of an experience is sought through one's own consciousness of the studied phenomenon. One takes in perceptions and comes into "knowing" and "understanding" through an interaction with the object/phenomenon in question, which results in a perception of reality of the phenomenon. In other words, "one takes in sensory information to which conscious awareness is directed, and about which some sort of interpretation can be made…[and] it is the intentional direction of consciousness towards an object that gives it reality" (Jackson, 2016, p. 442). This thorough and intentional examination results in discovering an essence of the phenomenon (Jackson, 2016).

The phenomenological methodology I drew from in this study is Interpretive Phenomenological Analysis (IPA). As a contextual approach, IPA recognizes that people's lives are embedded in social and cultural environments. IPA also recognizes that people make sense of their experience through self-reflection and self-interpretation. In addition, the researcher uses reflection and interpretation when attempting to make sense of others' experiences, thus resulting in a dual interpretive process. IPA also involves a dual analytic process. The researcher endeavors to take an "insider stance" to understand the experiences true to the participants' perspectives, as well as an "outsider stance" to understand how the participants are making sense of their experiences (Braun & Clarke, 2013).

In the process of phenomenological research the researcher does not begin as blank slate ready to take in information nonjudgmentally, however. He or she will probably have had some previous experience with the phenomenon, thus sparking an interest in researching it. Initial assumptions are important to recognize as these will color the lens of the researcher's perceptions. An honest and thorough epoché will bring to light any preconceived judgements, attitudes, or beliefs and allow a broad understanding to develop. I share my own epoché below.

Epoché

My interest in this study stems from my experiences working with actively dying hospice patients. Along my educational and career path I was not specifically trained in how to approach a music therapy session with a dying person. In addition, I personally grappled with feelings about death and my own mortality. Admittedly, I entered the hospice setting with a sense of uncertainty. In my experiences with actively dying patients over the past five years I have felt the intense power of the music and I realized I had an important responsibility in providing both music and presence that would hold a sacred space for the patient and others present. My experiences with death and dying and music have been profound and have affected me deeply.

I recall one day of work when I was present at the deaths of two patients, which is highly unlikely for any hospice professional. When I arrived for my first visit of the day at a nursing home the wife of the patient was distraught and grieving, and when I offered music she took a deep breath and nodded. She requested "How Great Thou Art"

and held her husband's hand. As I looked at this man I noticed his chest was not moving. He had already died. I crumbled a little inside knowing I would be the one to tell his wife. I played through the song as his wife squeezed his hand and cried. When the song I ended I softly said "I think he's passed." She didn't believe me at first, but with confirmation from the nurse she acknowledged his death. Many staff gathered around her as she sobbed, and I stayed for a while to support her. Being with her I felt at a loss of words. I also felt what I understood to be her grief, and it was so raw. I left the building shaken, feeling in awe of a life's transition as well as the accompanying grief.

Later, after a team meeting and another visit, my last visit of the day happened to be at the same facility. The hospice nurse was there and asked me to see a patient who had just been admitted and was actively dying. A practicum student was with me and I asked if she felt ready to observe this session, and she said she was. The older female patient had no family with her. The nurse said she was a "devout Catholic" so I played Catholic hymns. Given her labored breathing with periods of apnea (extended time between breaths) I could tell she was close to death. Feeling somewhat breathless as I sang, I kept guitar chords going softly as I recalled lyrics of well-known Catholic hymns and prayers and told her God was holding her and bringing her to him, and it was ok to go with him. As I sang *Amazing Grace* a moment of time slipped by where she did not take another breath and the pulse I could see in an artery in her neck stopped throbbing. I felt frozen in this moment. I looked at my practicum student, who was crying. Again, I felt shaken with no words. I had watched her die. I might have helped her die. It was so final. It was so beautiful.

This is not a typical day of work in hospice for me. In the past five years that I have been working in this setting I have been present for five deaths, which include the two I just described. This particular day emphasized the deeply profound nature of the work, and I still look back on that day with awe, knowing those experiences affected me on a spiritual level and helped me grow as a human being.

I am often asked “How do you work with dying people? Isn’t that difficult?” It is challenging to answer but the best I can express it is that while there are some challenges in the work, it is amazing and fulfilling in so many ways. Every day I am reminded not to take life for granted and every moment I have with my family is a gift. The work helps me live a fuller life!

With this project I was hopeful that through both verbal and creative means of exploration I could come to a deeper understanding of how to answer these types of questions, and in turn help others understand the answer to these questions. This work is different from any other type of music therapy practice, and I entered into this research with wonder about how we can more accurately describe what it is like for music therapists to work with actively dying hospice patients.

Chapter 2: Review of the Literature

The hospice approach involves a team of professionals attending to the patient's physical, emotional, and spiritual well-being to preserve dignity and comfort at the end of life (National Hospice and Palliative Care Organization, 2016). About 1.2 million people received hospice services in 2011 and there were at least 3,700 hospice care agencies in the United States in 2012 (Centers for Disease Control and Prevention, 2015). Accordingly, the prevalence of non-required referral-based services, such as music therapy, have increased in the hospice setting (Silverman & Furman, 2014).

The word "hospice" comes from the Latin work *hospes*, which refers to a place of shelter for weary travelers. The modern philosophy of hospice was developed by Dame Cicely Saunders, who believed that dying is a physical, psychosocial, and spiritual experience, and support should be provided to all aspects of the person's needs. She created the first hospice home, St. Christopher Hospice, in London in 1967. Following her guidance and training the hospice movement advanced in the United States in the late 1970s (National Hospice and Palliative Care Organization, 2016).

Elizabeth Kubler-Ross's work, including the seminal publication of *On Death and Dying*, in the late 1960s and early 1970s advanced awareness of the needs of dying at a Federal level, and after much hard work the Medicare hospice benefit was enacted in 1986. In 1993 hospice was recognized in President Clinton's health care reform proposal, which officially accepted hospice as part of the health care continuum and as

a fully covered Medicare benefit (National Hospice and Palliative Care Organization, 2016).

Domains of hospice care include pain and symptom management, psychological and psychiatric aspects of care, social aspects, spiritual/religious/existential aspects, cultural aspects, care of the imminently dying, and ethical and legal aspects of care (Strada, 2013). Hospice philosophy recognizes the patient as a whole person with end of life needs within physical, emotional, and spiritual realms, and support is also provided to the caregivers, families, and loved ones (Hilliard, 2005) by an interdisciplinary team. Required disciplines under the Medicare benefit are nurses, social workers, spiritual care providers, physicians, home health aids, volunteer coordinators, and grief counselors. Non-required disciplines include referral-based services (music therapists, massage therapists, physical therapists, respiratory therapists, art therapists, etc.) (Hilliard, 2005). Each discipline uses its specialized area of expertise to attend to the needs of hospice patients and families, and the team meets on a regular basis to coordinate plans of care.

The music therapist serves on the interdisciplinary hospice team and receives referrals from the team based on their assessments and need for services. Referral reasons may include pain and discomfort, anxiety, fear, dyspnea, disorientation, confusion, nausea, coping difficulty, depression, withdrawal, isolation, difficulty expressing or communicating thoughts and feelings, difficulties exploring spirituality or spiritual issues, and cultural language barriers. Following the referral, the music therapist assesses the patient and notes significant responses. The most pressing needs

are addressed first, and upon symptom stabilization other aspects of the patient's personhood can be explored in music (Mandel, 1993). A therapeutic relationship is developed, through which there are possibilities of healing and finding acceptance (Hogan, 2006). "Ultimately, the music therapy assists terminally ill patients in finding a path of acceptance and existential resolution from which to leave their bodies, separating themselves from this world to the next" (Hogan, 2006, p. 70).

The Dying Process

While a patient may enroll in hospice close to death, it is common for the disease progression to take weeks or months before moving into the active dying stage. The bulk of hospice work involves symptom management and psychosocial/emotional support. When the person does begin to show indications that end of life is near, there are signs and symptoms that accompany the "pre-active" and "active" phases of dying. It should be noted that each person's dying process is unique, and none, one, some, or all of the following symptoms may be experienced. In the pre-active phase, which is about one to three months prior to the death, the person exhibits increased weakness and lethargy, increased dependence on caregivers, withdrawal from interactions with others, decreased food and fluid intake, difficulty swallowing, disorientation, seeing and speaking to others who have already died, restlessness, and incontinence (Strada, 2013; Karnes, 2014). One to two weeks prior to death there may be an increase in disorientation and physical changes that include lowered blood pressure, changes in pulse, fluctuations in body temperature, breathing changes, and changes in skin color, hands, feet, and nail beds (Karnes, 2014).

From this state the person transitions to the active dying phase, which is one to two days, or hours prior to death. Some people may experience a surge of energy where they become alert, talkative, and may even ask for a meal. Additional symptoms in this phase include restlessness and increased confusion, and eventually the person becomes unresponsive. Physical signs of imminent death include breathing pattern changes with apnea (stopped breathing for 10-45 seconds) or rapid and shallow breathing, congestion, open eyes with a glassy stare, decreased circulation causing mottling (purplish tones) to the knees, ankles, and elbows (Strada, 2013; Karnes, 2014).

As mentioned before, the dying process is unique to each individual. The timelines mentioned in this section are not always the case; for example, some people remain in the active dying stage for days (Karnes, 2014). A team of hospice professionals continually assess pain, shortness of breath, confusion and agitation, terminal congestion, as well as other physical symptoms, and adjust interventions as needed. In addition, the changes experienced in the pre-active and active phases are often difficult for family and loved ones to watch, and the hospice team attends to their needs for emotional and spiritual support (Reith & Payne, 2009).

The Psychological Experience in the Dying Process and the Role of the Music Therapist

In an article geared toward music therapists, West (1994) discusses four phases of psychological and spiritual phases of the dying. Phase 1, the Early Phase, is the period of adjustment to the terminal diagnosis. Psychological responses may include balancing hope for cure with realism, adjustment to role changes and body image, shock,

numbness, denial, fear, panic, emotional flooding, anger, sadness, and vulnerability. Phase 2 is the Stabilization Period where the person must adjust to living with dying. This phase may include processing "unfinished business," life review, preoccupation with symptom management, periods of emotional stability, seeking support, social contact, and spiritual help. Phase 3 is called Disease Progression. The person must now adjust to more losses as they experience decreased functioning and energy. There may a decision to fight or surrender, and there may be increased pain as the disease progresses, as well as confusion, agitation, aphasia, and increased sedation to control these symptoms. Emotions may include fear of death, emotional regression, and deepened grief.

Nearing the active dying stage in Phase 4 (Endstage, Death), the person experiences detachment, disengagement, adjusts to sensory changes, focuses on internal tasks of death, and may demonstrate paranormal or spiritual experiences (West, 1994). West describes the role of the music therapist as "a witness and support person…a listener, both to the inner and outer experience of the session…serving as a mirror, validating the experience of the dying" (West, 1994, p. 119). She describes the role of the music as a container to hold and organize feelings as the patient confronts the psychological tasks of dying. She warns that the music is powerful and can become overwhelming if the music therapist is not sensitive to the patient's responses.

As the patient moves into the dying process the music should become simpler with longer periods of silence. The music therapist supports the patient by providing sounds and music that promote "surrender, focus of attention, and movement through

the transition process of leaving the body" (West, 1994, p. 121). This may sound like long, sustained tones, smooth melodies, and return to tonal centers within improvised music. The music therapist uses "sensitivity, intuition, and astute observation" (p. 121) while providing music that supports the physical and psychological aspects of the person who is dying, as well as the emotional states of the family (Krout, 2003).

Music Therapy Research Evidence: Objectivist Studies

There has been an increasing amount of research and discussion in the literature on music therapy in hospice and empirical research has studied the effects of music on symptoms associated with end of life. While these studies are helpful for justifying the effectiveness of certain music therapy interventions, the focus of interventions are for needs and symptoms during earlier phases of disease progression where the patients are relatively stable and able to consent to participate. There are no quantitative studies that investigate music therapy with actively dying hospice patients, and this may be because of ethical concerns. Ethical concerns in research with actively dying hospice patients include not being able to gain consent, inability of a participant to change their mind once consciousness shifts as part of the dying process, and where to draw the line out of respect for the dying process (Lawton, 2001).

That being said, findings from the existing objectivist studies are helpful in guiding the music therapist when working with actively dying patients. One of the first objectivist studies was implemented by Curtis in 1986. She found that music therapy positively affected pain perception, physical comfort, relaxation, and contentment in hospice patients prior to the active dying phase. Whitall's (1989) results showed

decreased heart rate and blood pressure following music therapy sessions with eight stable terminally ill patients. In a later study Gallagher, Lagman, Walsh, Davis, and LeGrand (2006) found that song choice was effective in providing enjoyment, decreasing anxiety and depression, decreasing pain perception, developing coping skills, improving mood, and providing distraction. Another study found that live music was found to be more effective than recorded music on pain reduction and comfort (Clements-Cortés, 2011).

In an analysis of 90 music therapy sessions with 80 hospice patients Krout (2001) found that active and passive music therapy experiences were effective in pain control, physical comfort, and relaxation from pre- to post-test in a single session. Significant effects on anxiety were found in another study (Horne-Thompson & Grocke, 2007) where live familiar music, singing, music and relaxation, music and imagery improvisation, music assisted counseling, reminiscence, and listening to recorded music were implemented based on the patients' presenting needs. Using a randomized control design with 25 participants a significant reduction in anxiety was found in the experimental group. Results showed significant reductions in anxiety, as well as pain, tiredness, and drowsiness.

Using the Hospice Quality of Life Index-Revised, Hilliard (2003) found that the experimental group of participants with terminal cancer who received music therapy scored significantly higher in measures of quality of life. Eight subjects participated in the study and those in the experimental group received at least two music therapy sessions. Music interventions included song choice, reminiscing, singing, music listening,

lyric analysis, instrument playing, song parody, funeral planning, song dedications, and music-assisted supportive counseling. In another study, Wlodarczyk (2007) studied the effects of music therapy on spirituality. This study used an ABAB design with 10 hospice patients and a researcher-adapted spirituality questionnaire. Music interventions include singing and playing guitar using familiar songs, song choice, improvisation, songwriting, life review, song dedications, and sing-a-longs with family and friends.

Music Therapy Research Evidence: Case Studies

There are many case examples of music therapy in hospice and palliative care (Aldridge, 1999; Bruscia, 1991; Bruscia, 2012; Dileo & Loewy, 2005; DiMaio, 2010; Meadows, 2011) and like the objectivist research most describe a therapeutic process that occurs during the period of stability before the active dying process. There are two case studies in the literature that discuss music therapy in the active dying process of a hospice patient.

Potvin (2015) described a case within a context of ritual drama with a hospice patient who was actively dying. He described the role of ritual drama, which involves the exploration of new roles in a process of separation, liminality, and reintegration. He acknowledged each person's role as the patient moved through the active dying process, and supported a transformational process with music. Potvin, mindful of cultural and spiritual traditions, supported the patient and family in processing, connecting, celebrating, grieving, and discovering how to move forward. Self-examination of his own countertransference was a critical part of the process.

Hogan (1999) described her work with a hospice patient that included pain and anxiety reduction, emotional support, relaxation, reminiscing, family support, and comfort during a period of stability and at end-of-life. A tape of songs that were meaningful to the patient was compiled and used at night when he became restless. On the day the patient died the music therapist sat with him and his wife and they listened to the tape. As the song *Danny Boy* played the patient died. As the tape continued family arrived and, supported by the music, they shared meaningful moments in their grief and sorrow. Several songs from the tape were played at the funeral, and the wife said listening to the tape was helpful in her time of bereavement. Hogan did not comment on her experience when working with this patient. These case studies are helpful in developing an understanding of how music therapy can support hospice patients when actively dying, but more formal approaches, such as phenomenological research, could provide more clarity.

Music Therapy Research Evidence: A Literature Review on Spirituality

Spiritual issues and concerns are one of the primary components of hospice care, and music often supports spiritual beliefs and experiences. A recent literature review by Hong (2016) revealed areas of spirituality addressed by music therapists with hospice patients. These issues include the need to transcend one's current situation, need to find meaning, need to restore or affirm one's sense of hope and faith, loss of spiritual/personal connection with others, loss of identity and lack of connection to oneself, need for resolution or closure, and feelings of anxiety, worry, fear, and denial. Interventions found within the studies include music entrainment, musical life review,

chanting for the patient, music listening for relaxation, music and imagery, music listening to support prayer and worship, lyric analysis songs that contain spiritual themes, and song choice (Hong, 2016).

The sources in this literature review provide a helpful and informative framework for music therapists on spiritual needs of hospice patients and music therapy interventions to address those needs. However, spiritual needs specific to actively dying patients and their families were not distinctively addressed, thus confirming the need for more investigative attention to music therapy during the active dying phase.

Caregivers' Experiences of Music Therapy

It is not only the patient who music therapists in hospice work with, but also the family members. Two studies explicate the experiences of caregivers of terminally ill family members. Through a research method of naturalistic inquiry, Magill (2009) interviewed seven bereaved caregivers about their experiences in music therapy. A data analysis process of coding for themes revealed the caregivers experienced joy in seeing their loved one happy. They also reported feelings of empowerment by being able to contribute to the music therapy sessions. Spiritual themes emerged as they reflected on past/remembrance, present/connectedness, and future/hope. In addition, they felt connected to self and others during the music therapy session. The overarching theme that emerged was "meaning through transcendence" as they were able to reflect on their experiences and connect with the love, joy, and peace that was felt in the dying

process. This study revealed that pre-loss music therapy for adult hospice patients are valuable and beneficial for their caregivers as well.

Lindenfelser, Grocke, and McFerran (2008) examined bereaved parents' experiences of music therapy with their terminally ill child. Using the methodology of phenomenology data was analyzed from seven interviews, with the emergence of five themes. The themes were (1) music therapy was valued as a means of altering the child's and parent's perception of the situation in the midst of adversity, (2) music therapy is a significant component of remembrance, (3) music therapy was a multi-faceted experience for the child and family, (4) music therapy enhanced communication and expression, and (5) perceptions and recommendations of improving music therapy. The "global essence" of this study revealed that parents remembered music therapy for their child as meaningful and left them with positive memories of their child being happy. These two studies reveal the "ripple effect" benefits of music therapy for hospice patients from pre-loss to post-loss, and confirm the necessity of music therapists to involve family members with awareness of what they might be experiencing.

The Music Therapist's Experience of Working in Hospice

There are only two research studies that explore the music therapist's experience of working with the actively dying. An aspect of the music therapist's experience was present in Forinash and Gonzalez's (1989) phenomenological exploration of a music therapy session with an actively dying hospice patient. The authors used a modified version of Ferrara's phenomenological approach to analyzing music, and descriptively wrote about the client's background, what happened in the

session, analysis of the music, the patient's responses during the music, and the music therapist's experiences. What emerged in the metacritical evaluation was the music therapist's awareness of the relationship between the client's breathing and the music, as well as images that were influenced by the music, such as feeling/seeing the client reach her hands toward God. Essentially, the music therapist relied on clinical observations and personal experiences as influential in her provision of music therapy.

The second study is most influential to my project because it directly investigates music therapists' experiences with actively dying patients through phenomenological inquiry. Dorris (2015) interviewed four music therapists and found themes common to music therapists who provided hospice visits during imminent death: ongoing assessment, intuitive processes, countertransference, and the role of aesthetics and transformation. Within these themes the following sub-themes themes emerged:

- Importance of knowing the client's background
- Physiological responses can indicate internal experiences
- The music therapist should be flexible and adaptive in the moment
- Intuitive processes are extremely important
- Influence of countertransference
- Responsibility to take on a role that transforms the experience in a meaningful way
- Central goal is to help the patient transition meaningfully and without discomfort

- The music therapist engages in a collaborative process with loved ones and provides a meaningful experience for them as well
- Music therapy can reveal beauty and meaning in the midst of pain and suffering
- Music therapy can transform the experience and environment

Other literature has included the music therapist's personal reactions and responses, though not within a phenomenological research context. Potvin (2015) disclosed his personal connections to his patient Mitzi and her family in the epoché section of his article. He revealed his religion and religious beliefs and his history of his mother surviving cancer. His countertransference manifested in re-experiencing guilt over not doing enough for his mother at the time she was sick, and the overlap of spiritual and cultural practices with the family. This information was provided to help the reader understand how his role developed with the patient and family, how he understood their situation, and what was involved in his approaches and thought process as the patient declined and went into the active dying process.

DiMaio (2010) included personal responses of her experiences using Music Therapy Entrainment with hospice patients who are in pain. She wrote that she made personal discoveries in her connections with the patients, was able to respond authentically, realized she could ask fewer questions, was aware of her countertranferences, and was sensitive to the effect of her presence and focus on her ability to read nonverbal cues. She also reported feeling anxious about the patients' pain and felt a responsibility for their pain. She realized she needed to trust herself and the

process, and to allow the interaction with the patient and the music to unfold. While helpful to know what she was experiencing, these reactions were not in response to hospice patients who were actively dying.

Related Studies

Several related research studies have explored lived experiences of music therapists that relate to the present study, and these include intuition, spirituality, and presence in music therapy. Through naturalistic and hermeneutic inquiry, Brescia (2005) found that the music therapists she interviewed (some who had experience in hospice) used intuition and did so through the receipt of physical messages, emotional messages, auditory messages, and visual messages. They also described their intuition coming from a spiritual realm (a greater consciousness). Conditions involved in using intuition were trust, deep listening, self-awareness, previous experience, and relationship with the client.

Marom (2004), through phenomenological inquiry, found that music therapists have spiritual experiences and these may be witnessing the client's spiritual experience, sharing a spiritual experience with the client, or having a personal spiritual experience. The music serves to enter into the spiritual experience, hold it, intensify it, and process it. Spiritual experiences were reported to happen within receptive, compositional, improvisational, and re-creative experiences. The music therapists discussed their personal experiences in noticing the spiritual properties of music, having self-awareness and maintaining professional boundaries, experiencing a strong sense of empathy for

the client(s), remaining open and supportive of the client's experience, and holding a safe space for the clients to have a spiritual experience.

Being present to clients was explored by Muller (2008) in a phenomenological investigation. He found that both intention and openness to the "as yet unknown" are involved in being fully present with clients. Additionally, the music therapist must effectively work with emotion, which involves identifying emotions and using them in the process. Finally, the music therapist must maintain a balance of being in the client's world, being in the music, and being self-aware. I have found intuition, spirituality, and presence as important aspects of my work with actively dying hospice patients, and I anticipated these topics to emerge in the data of this study.

While many studies have evaluated and discussed music therapy for needs associated at the end of life (symptoms, etc.) the bulk of this literature is focused on patients in the period of stability prior to the active dying phase. There are very few sources of literature that address music therapy with actively dying hospice patients. Additionally, there is even less that describe the music therapist's personal experience with actively dying hospice patients. Many music therapists work in the hospice setting and providing music therapy at this final stage is a regular part of the job. Given the profundity of being with an actively dying person it seems worthwhile to explore how music therapists experience their work.

Phenomenological Inquiry to Address Research Questions and Design

Several studies in this literature review used the methodology of phenomenology, which is the methodology chosen for the current study as determined by the research questions. Phenomenology "seeks to discover and describe the structure and meaning of a phenomenon that makes it intrinsically what it 'is' – its essence" (Jackson, 2016, p. 441). It is an appropriate methodology for research questions that are subjective and non-positivistic, where rather than a conclusion is found, a human experience is more deeply understood (Marom, 2004).

Several examples of research questions addressed by phenomenology as a methodology are found in the studies described in the previous section. Marom's (2004) research questions in her study on spirituality in music therapy were

- What were some examples of incidents in which the music therapy process became spiritual?
- How did the therapists who conducted the sessions view those moments as spiritual, and
- What were the experiences of the music therapists who conducted the sessions (i.e. their thoughts, feelings, intuitions, and actions)?

Muller's (2008) research questions in his study on the music therapist's experience of being present were

- How does the music therapist's experience of being present unfold? and
- What defines being present as a music therapist?

These questions warranted a phenomenological methodology because it is seeking to understand the nature of the experience itself. This application of phenomenology is consistent with the present study which asked the following research questions:

1. What do music therapists experience when working with actively dying hospice patients?
2. How do music therapists prepare for these visits, and then process their experiences afterward?

My aim is to gain a sense of understanding of the parts and the whole of the experience from the music therapist's perspective from pre-session to post-session. Essentially, *what is it like for a music therapist to work with an actively dying person?* The only way I can gather information to explore this topic is from music therapists who have worked with dying hospice patients.

Conclusion

This study explored what it is like for music therapists to work with actively dying hospice patients. What do music therapists experience in preparation, in the moment, and afterward? There is relatively ample evidence of the effects of music therapy on clinical symptoms, as well as descriptions of the process of music therapy with patients on hospice. There is little, however, that describes the music therapist's experience. In order for our profession to learn and grow this aspect of clinical care must be addressed. A deepened understanding of the music therapist's experience will in turn

enhance the breadth and depth of the music therapist's skill set, thus increasing the quality of therapeutic services at the most sacred time of life: death.

Chapter 3: Method

Methodology

The research design of this study is phenomenological inquiry. Phenomenological inquiry seeks to "explore and explicate the nature of a phenomenon through first-person experience" (Jackson, 2016, p. 441). It searches for the essence of the phenomenon. Rooted in phenomenological philosophy, the quest is not for a "truth" but for a subjective interpretation from human beings who have experienced the phenomenon in question. Humans know their experiences through their perceptions and senses, and while perceptions may be different among people, finding the essence of a phenomenon becomes a shared reality. The purpose is to explore lived experiences in order to expand the breadth and depth of one's understanding of the phenomenon (Jackson, 2016). In this study I was seeking to explore the lived experiences of music therapists working with actively hospice patients.

Interpretive Phenomenological Inquiry (IPA) is a methodology within phenomenology that I used to guide the development of the method. IPA involves a detailed examination of the participant's life-world and attempts to explore perceptions and meanings of life events or experiences. Data is gathered through semi-structured interviews and analyzed through a process of looking for themes. Themes are connected and then cross-connected over cases. Along the way the researcher attempts to understand the participants' experiences from their point of view, and also steps back and critically analyzes and questions the perceptions (Smith and Osborn, 2007).

I chose three modalities to explore experiences of working with actively dying hospice patients: a verbal discussion, drawing a mandala, and music improvisation. I incorporated modalities of creative expression in hopes that new and/or deepened awareness would emerge that would contribute to the understanding of the phenomenon in question. A mandala is a piece of paper with a circle already drawn on it. Used by art therapists, and often by practitioners of the Bonny Method of Guided Imagery and Music, it is believed that drawing in a reflective way brings new awareness and insights (Bonny & Kellogg, 2002/1977). Music improvisation is one of four methods of music therapy, and commonly used by music therapy clinicians for the purposes of psychological growth and promotion of awareness and insight (Bruscia, 1987). These forms of creative expression seemed appropriate in exploring what I often find so difficult to express, which is what it is like to provide music therapy to a person who is in an active process of dying.

Trustworthiness

Because I also have experience with this phenomenon I made a significant effort to conduct the study with openness and awareness of my knowledge and experiences and how those might impact my perceptions throughout the process. This proved challenging because it was nearly impossible not to relate to what the participants shared with me. However, it was necessary to remain as objective as I could in order to best understand their experiences. I engaged in a practice of triangulation to ensure the trustworthiness of this study: journaling, bracketing, member checking, and consultation.

Journaling

I kept a journal where I recorded what I considered in each step of the study. I made notes on Dorris' (2015) study, which involved similar research questions and methodology, and noticing the similarities and differences of our studies helped me solidify necessary steps in the method. I also jotted my personal reactions, thoughts, questions, and feelings as they arose. Keeping these in my awareness helped me remain open to understanding the research process as it unfolded.

Bracketing

I used bracketing during the interviews, which proved to be quite challenging. Bracketing involves setting aside personal thoughts, beliefs, values, and feelings in order to best understand the information from the other person's perspective (Jackson, 2016). As the participants spoke sometimes my own thoughts, feelings, and memories of patients would surface, and I recognized that my own experiences and emotions were distracting me from what they were sharing. I made every effort to clear them away and remain open to what the participants were saying to ensure the interview remained focused on the participants' experiences.

Member Checking

I sent the transcripts to the participants so they could clarify, change, or modify what they shared, which was meant to ensure I had the information exactly how they wanted it expressed. I received two of the transcripts back with no changes, and the third was not sent back by the participant so it was used in its original form.

Consultation

I consulted with Dr. Kenneth Bruscia who is an expert in research as well as mandala and music analysis. My primary question for him regarded the process of data analysis, and if there was anything more I needed to consider when looking at the mandalas and music. This conversation resulted in a clearer vision of how to use the participants' creative expressions, which was to use the participants' verbal descriptions of them as well as my observations.

Participant Recruitment

Following IRB approval from Augsburg College and completing CITI (Collaborative Institutional Training Initiative) training I moved forward with recruiting participants. Criteria for participation in this study were (1) board certification in music therapy, (2) at least five years full-time (or equivalent) experience in the hospice setting, and (3) currently working in hospice. The criteria of length of experience was chosen to ensure a significant number of experiences with dying hospice patients, with ample time to process these experiences and develop perspective from them. In addition, I hoped that because the participants would be currently working in hospice the experiences they would share would be freshly present to them, thereby providing depth and richness to the data that would be collected. (I later modified the criteria of currently working in hospice for one participant, Phyllis, and this is explained below.)

Three music therapists participated in this study. Two were recruited from a notice I posted on a closed-group internet forum for hospice and palliative care music

therapists (see Appendix A), and one was referred by someone who originally wanted to participate but was unable. When I received emails from interested music therapists I replied with detailed information about the study and attached the consent forms for their review, so they would understand as fully as possible what they would be agreeing to (see Appendices B, C, and D). No compensation was provided for participation.

Participants

Barbara

Barbara described her approach to hospice music therapy as eclectic, and drawing mostly from humanistic theory. She had worked in hospice for nine years, and had been a music therapist for a total of 33 years, working in other settings that included schools, adult day care, psychiatric facilities, and medical/hospital. She also had a background in the Bonny Method of Guided Imagery and Music. She described her caseload of hospice patients as located in the rural south, with economic and cultural diversity. She reported working with actively dying patients at least one to two times per week.

Phyllis

A participant that was originally recruited cancelled due to a family emergency. This person contacted another music therapist (Phyllis) in her area who was able to participate in the study. Phyllis was board certified with twelve years of full-time experience in hospice and palliative care, however she had not worked for six months following the birth of a child. With the support of my thesis advisor I decided to waive

the criteria of currently working in hospice in her case because she had a significant amount of experience with a comparatively short time away from the field. It seemed what she could share would be beneficial to this study.

Phyllis described her approach to hospice music therapy as influenced by humanistic and Jungian theory, with special attention to the emotional and cathartic shape to the session. She had a background in the Bonny Method of Guided Imagery in Music training, and this was also influential in her work. She described the patients she served as being mostly elderly, white, in the rural south, and economically diverse. She reported she had worked with actively dying patients about five times per week.

Tova

At the time of the interview Tova had ten years of full-time experience in hospice, and 17 years' experience overall as a music therapist, working also in special education and early intervention. She had also worked in pediatric hospice and palliative care. She described her approach to hospice music therapy as eclectic, and influenced by humanistic and existential theories, Buddhist psychology, and feminist theory (relational-cultural theory). She described her caseload as over 50% Catholic, many patients of Irish and Italian descent, and the majority in the middle class economic bracket, although she sees patients from all ends of the economic spectrum. She said about 40% of her caseload is quite diverse, and include Vietnamese, Greek, Armenian, African American, and Latino ethnic groups. About half her caseload are patients in private homes, and the other half are in care facilities. She also currently has a pediatric

caseload. She reported working with actively dying patients four to five times a week, with a majority of those patients residing at her company's hospice residence, which has 20 beds.

Data Collection

Interviews were conducted at locations convenient to the participants as I had to travel to their area of the country, and these included a classroom at a church, a conference room at a hotel, and a participant's living room in her apartment. Interviews lasted 90-120 minutes. I used an iPad with the application "Recorder," as well as an iPhone with the application "Voice Memos" to record the interviews. Both devices were password protected. I turned off the WiFi connections and used the "do not disturb" function so notifications would not sound.

Interviews began with reviewing the consent forms. I read through each form and left time for questions. Each participant signed forms that indicated their consent to participate, consent for me to use their direct quotes, and consent for me to record the interviews and take pictures of their mandalas (see Appendices B, C, and D). They signed a copy for me to keep as well as copy to retain.

I asked them to pick a preferred name to be used as a pseudonym for the study, and then asked about their years in the field, theoretical orientation, how often they see actively dying patients, and the basic demographics of their caseload (reported above). Then the interview involved questions about their experiences with actively patients. I had a list of questions I asked each participant at some point in the interview. As a semi-

structured interview, I allowed the interviews to take shape as naturally directed by the participants, and sometimes I asked follow up questions specific to what they shared. The questions I asked each participant were:

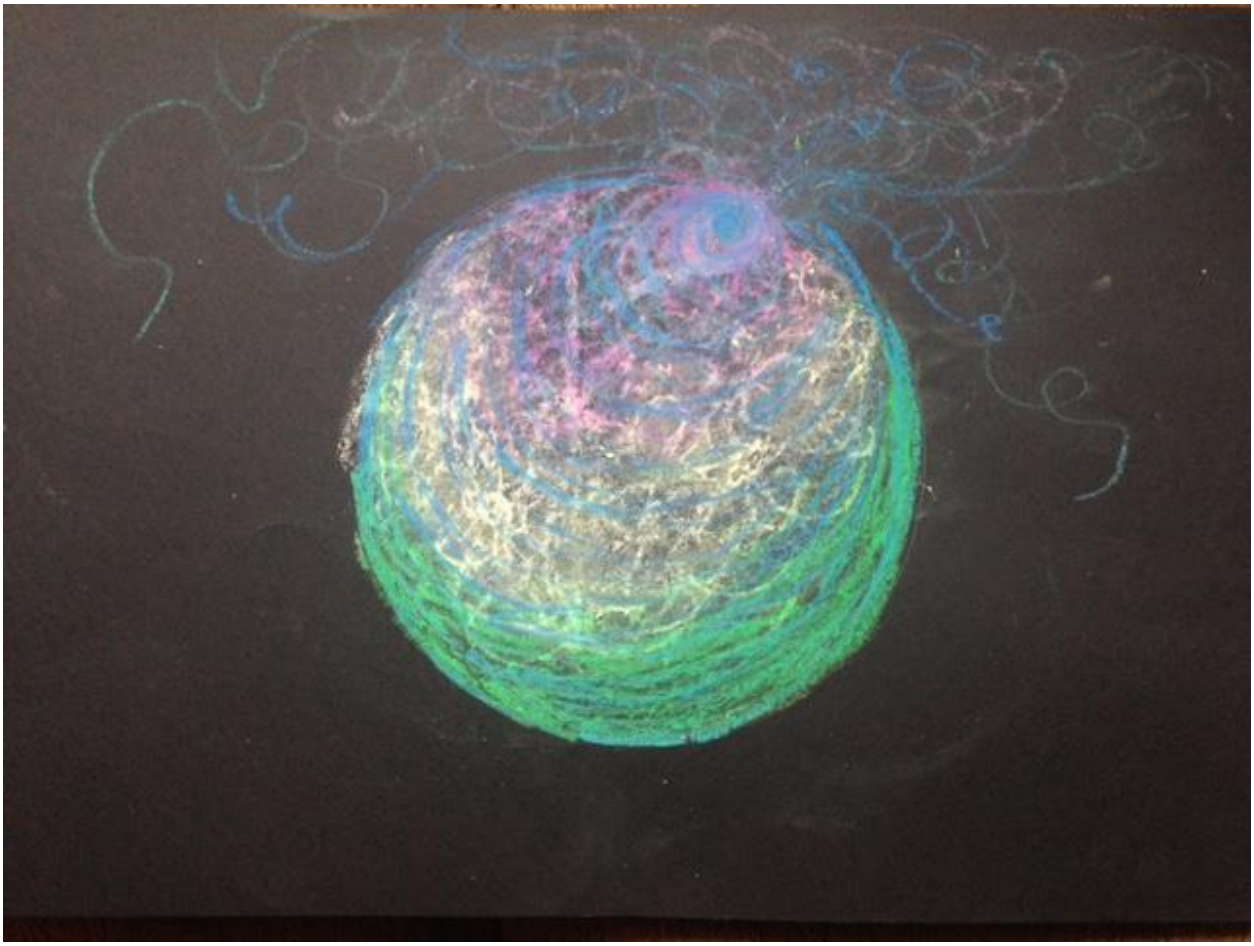
- Please share any general thoughts that come to mind as you think about what is like for you to work with actively dying hospice patients.
- Are there any specific times or patients that stand out in your memory?
- What are some important factors you keep in mind?
- What are your aims, intentions, or goals?
- Do you do anything to prepare for working with actively dying patients?
- Do you do anything to process your feelings afterward?
- What are your feelings in the moment?
- What is your personal experience of the music?

Following this part of the interview I gave each participant the option of drawing a mandala or making music next. Each chose to draw a mandala first. Each participant additionally reported having had drawn mandalas before, so I did not need to explain any further. They were given a choice of black or white paper, and each chose black paper. Interestingly, each said they had never drawn a mandala on black paper before. They were also given a set of oil pastels. I provided the following prompt:

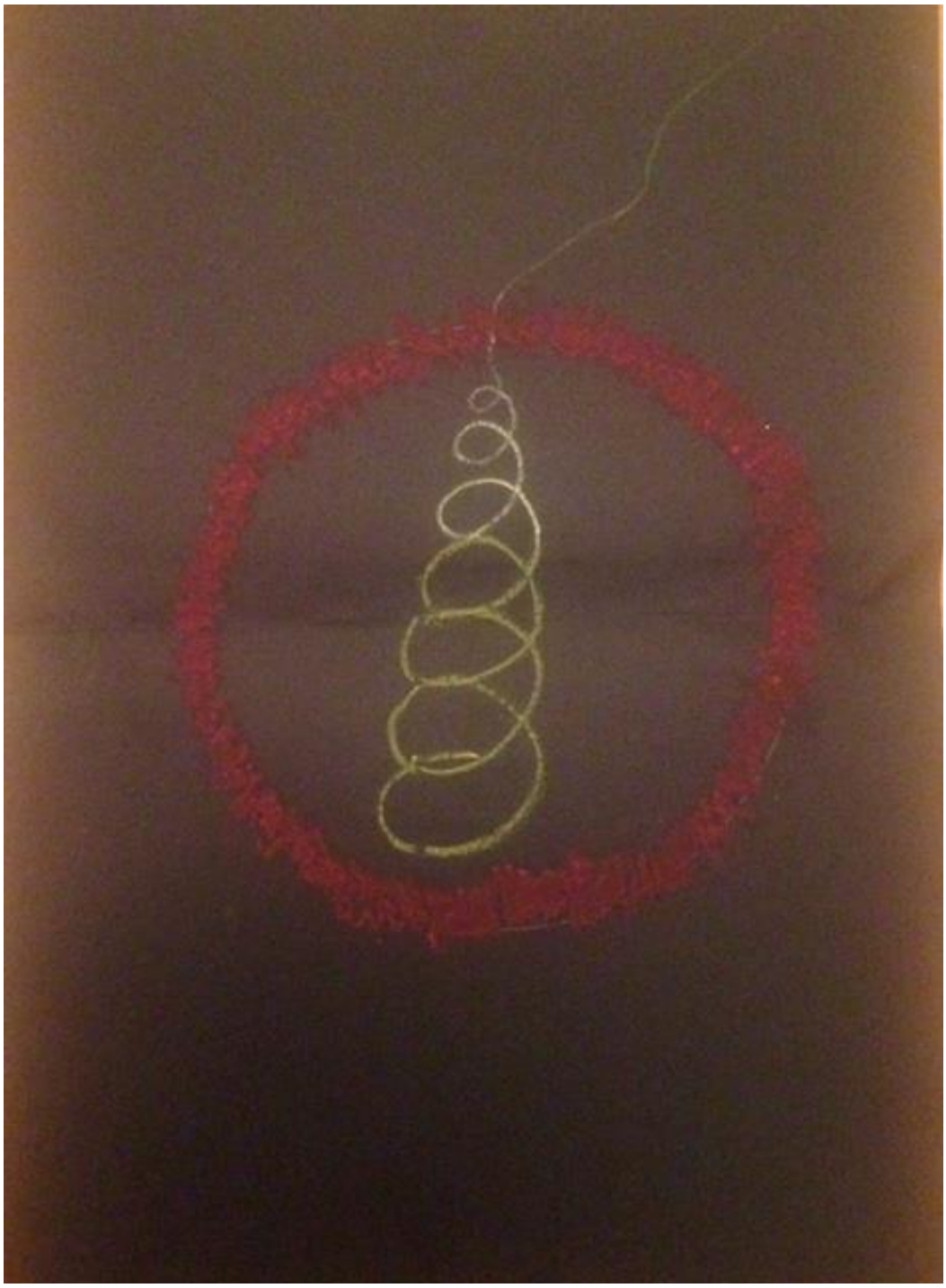
> *As you reflect on the experiences you just shared, continue your reflection of working with actively dying hospice patients as you choose colors to come onto the paper. Allow your experiences, thoughts, and feelings to guide you.*

The participants drew in silence, taking about 10-15 minutes. Afterward they shared what stood out to them about their mandalas. The mandalas are shown below.

Picture 3: Barbara's mandala



Picture 4: Phyllis’ mandala



Picture 5: Tova's mandala

Then each participant made music. I brought the following instruments and laid them on a table before the participants: Reverie Harp, Native American flute, chime

eggs, ocean drum, medium hand drum, small hand drum, two maracas, plastic hand-held jam block (similar to a cowbell) with mallet, tambourine, bells, rain stick, and vibratone bar (middle C). The arrangement of instruments looked like this:

Picture 6: Instruments available to the participants

I asked each participant to bring any instruments they would like for this portion of the interview. Phyllis brought a guitar, Barbara brought her own Native American flute and a guitar, and Tova had available hand held chimes and a set of Free Tones (similar to a pentatonic metallaphone). Each person improvised on the instruments for 5-10 minutes, and my role during the music remained as observer and listener. Afterward they shared

their thoughts. I have transcribed into words a description of the music each person made.

Barbara's Music

Barbara struck the vibratone moderately 3 times, letting the sound ring and fade. Then she picked up the ocean drum and let the beads roll around slowly, and lifting it so the beads would fall quickly and loudly. She lifted and turned the drum so the beads were continuously rolling, creating a swirling sound, with an ebb and flow of loud and soft. She did this for about one minute and 45 seconds. Then she played her Native American flute, which was in the key of E-minor pentatonic. She used the entire range of the notes, ascending and descending, using simple rhythmic and melodically-shaped phrases and occasional articulation with trills. The tone was warm with vibrato on notes that were held. The tempo was andante. She played for about two and half minutes, ending on a held and fading tonic note of E. Finally she played the vibratone again in the same way as before, striking it with the mallet three times, and letting the sound ring and fade.

Phyllis' Music

Phyllis picked up the blue maraca and shook it side to side with a loose eighth-note rhythm at about 120 beats per minute (bpm), slowing just slightly sometimes, and for about eighteen seconds. Then she played a steady quarter note rhythm at about 60 bpm for about 30 seconds, then returned to the first rhythm for about 20 seconds, and then played the final shakes slower and slower. She picked up the chime eggs, shaking

them so they rang consistently for about 10 seconds, then shook the shaker again a few more times.

Then she picked up her guitar, playing 9th chords with a steady strum at about 75 bpm. Her progression used suspended A major, E minor, and F-sharp minor chords. She began to vocally hum “mmm” on an A (above middle C) and down a fourth to E, then back up to A. Her vocal sound opened to an “ahh” on the same A and E and moved downward to a melody with D, C-sharp, and A. She repeated this melody, staying on C-sharp. Then she moved to C-natural, to D, and resolving to E. She then remained strumming on an A9 chord and hummed, improvising on A, descending to G-sharp and E, and back up again. She played the chords a few more times, and then the tempo slowed and the sound faded. She put down the guitar and picked up the jam block, “tocking it” two tocks at a time like a heartbeat, and did this seven times. Then she let the bead of the rain stick descend one time.

Tova’s Music

Tova began with the Native American flute. She explored different notes, letting her entire breath out on some, and allowing the sound fade. She explored different sounds on the flute, sometimes arrhythmic and sometimes playing rhythmically and melodically. After two minutes she began to play her Free Notes. She again seemed to be exploring, playing high notes, then low notes in an arrhythmic manner. Then she played an interval of a second, repeating it and going to a third. She continued playing in this way. The volume was soft. Then she moved to higher notes, playing seemingly

random melodic and harmonic intervals. Then she played one note, slowly. She very softly and quickly played upper notes, alternating, then together. The “exploratory” quality of playing continued. She played upper notes quickly, which sounded like a “sprinkling” of sound. Then she moved to the middle register, playing one note at a time, wandering up and down. She ended with a repeated high note.

She picked up her chimes and rang them in an upward motion for about 30 seconds. Then she played the Reverie Harp, plucking a few strings, and then strumming the entire range of strings. Her playing became quick, short strums randomly over the instrument, and briefly vocally “ooh”-ed for about ten seconds before letting the sound fade to the ending.

Data Analysis

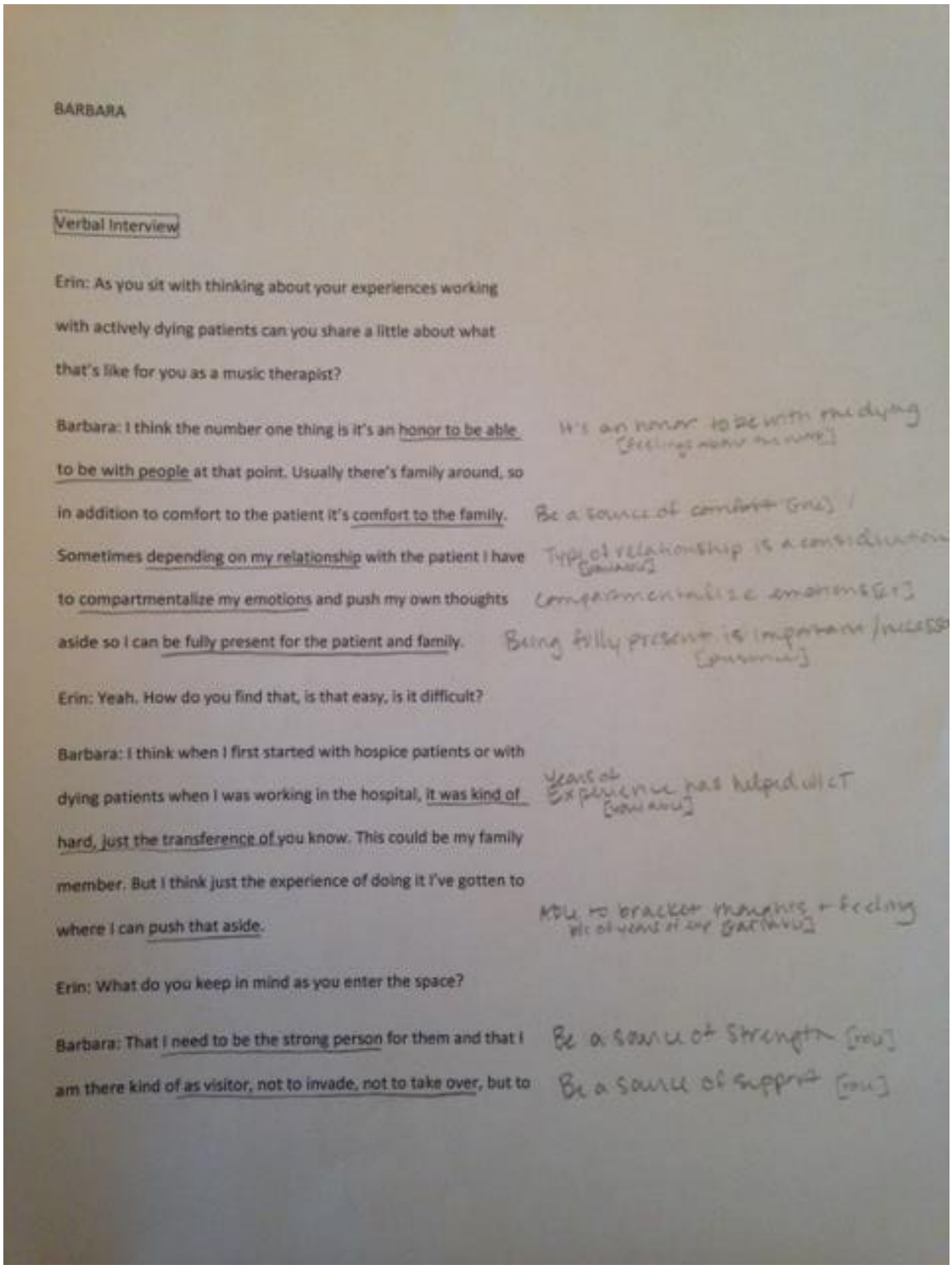
I prepared for transcribing the interviews and coding the data by reading selected chapters from Braun and Clarke’s (2013) *Successful Qualitative Research: A Practical Guide for Beginners*. Taking guidance from the concepts of IPA (Smith & Osborn, 2007) I engaged in the following data analysis process:

1. Transcription of interviews with member checking
2. Coding. Underlined and concisely described significant phrases
3. Assignment of preliminary themes to codes
4. Collation of codes to groups
5. Organization of themes and sub-themes

I transcribed the verbal parts of the interview as close to verbatim as possible, and then emailed them to the participants for their review. I included pictures of their mandalas, as well as an audio clips of their music. I asked them to review everything and to make changes, revisions, and additions directly onto the transcripts. Two participants indicated no changes were necessary. The third participant did not respond to my email so I used her transcript in its original form. In preparation for coding I changed the right-hand side margin to four inches, printed the documents, and hand-wrote codes next to the text. I interpretively assigned the codes a descriptive preliminary theme in parentheses. See an example of a page of Barbara's transcript below.

Data Preparation

While coding the transcripts I interpreted their words and assigned preliminary themes to each code. At this point I strived to understand their experiences from their perspectives. For example, next to Barbara's statement of "I think the number one thing is it's an honor to be able to be with people at that point," I assigned the code "It's an honor to be with the dying." I thought about what possible theme this code could fall under and I designated the preliminary theme to be "feelings about the work." I used the term "preliminary theme" to allow for changes and modifications of these themes and groupings of these themes to form final themes. The preliminary themes for each participant are tabled below, listing same and similar themes next to each other. It was interesting to note that some themes were formed from information shared after the mandalas and music. The preliminary themes in italics indicate that additional



BARBARA

Verbal Interview

Erin: As you sit with thinking about your experiences working with actively dying patients can you share a little about what that's like for you as a music therapist?

Barbara: I think the number one thing is it's an honor to be able to be with people at that point. Usually there's family around, so in addition to comfort to the patient it's comfort to the family. Sometimes depending on my relationship with the patient I have to compartmentalize my emotions and push my own thoughts aside so I can be fully present for the patient and family.

Erin: Yeah. How do you find that, is that easy, is it difficult?

Barbara: I think when I first started with hospice patients or with dying patients when I was working in the hospital, it was kind of hard, just the transference of you know. This could be my family member. But I think just the experience of doing it I've gotten to where I can push that aside.

Erin: What do you keep in mind as you enter the space?

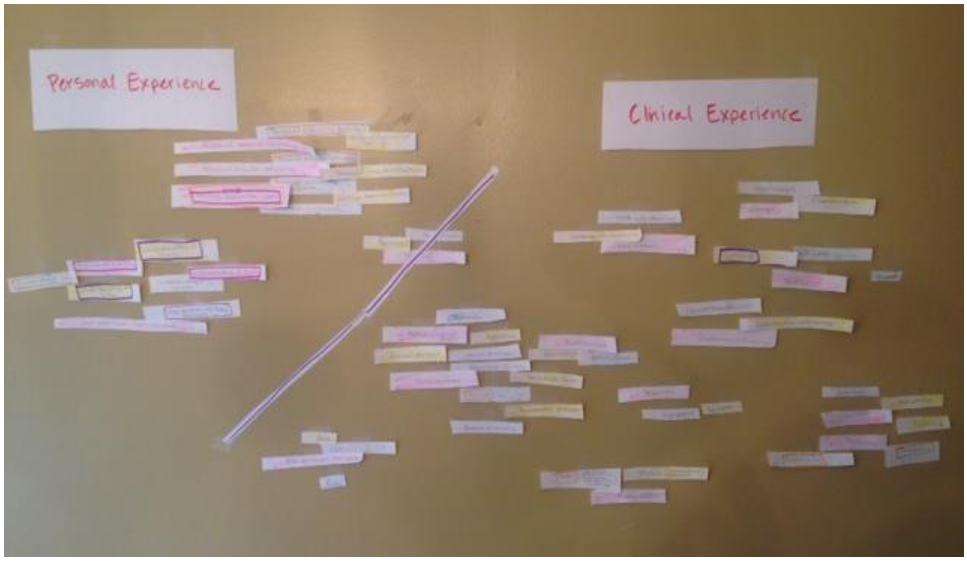
Barbara: That I need to be the strong person for them and that I am there kind of as visitor, not to invade, not to take over, but to

Picture 7: Example of coding process; one page from Barbara's transcript

information around that topic was shared after the mandala drawing and music making, and the preliminary themes in bold emerged only after the mandala drawing and music making. See Table 1.

Grouping the Data

I put each of these preliminary themes on a piece of paper and began taping them to a wall, grouping them as I went. I made groups of the preliminary themes and put them by related groups of preliminary themes. When I found I could not think of any more ways to move and relate the groups I stepped back and noticed two themes: clinical experience and personal experience. A small grouping of "spiritual" preliminary themes was located between these two groups, and since the participants described aspects of both their clinical and personal experiences when working with actively dying hospice patients as spiritual, I drew the line between the two groups over this group so that it is included in both.



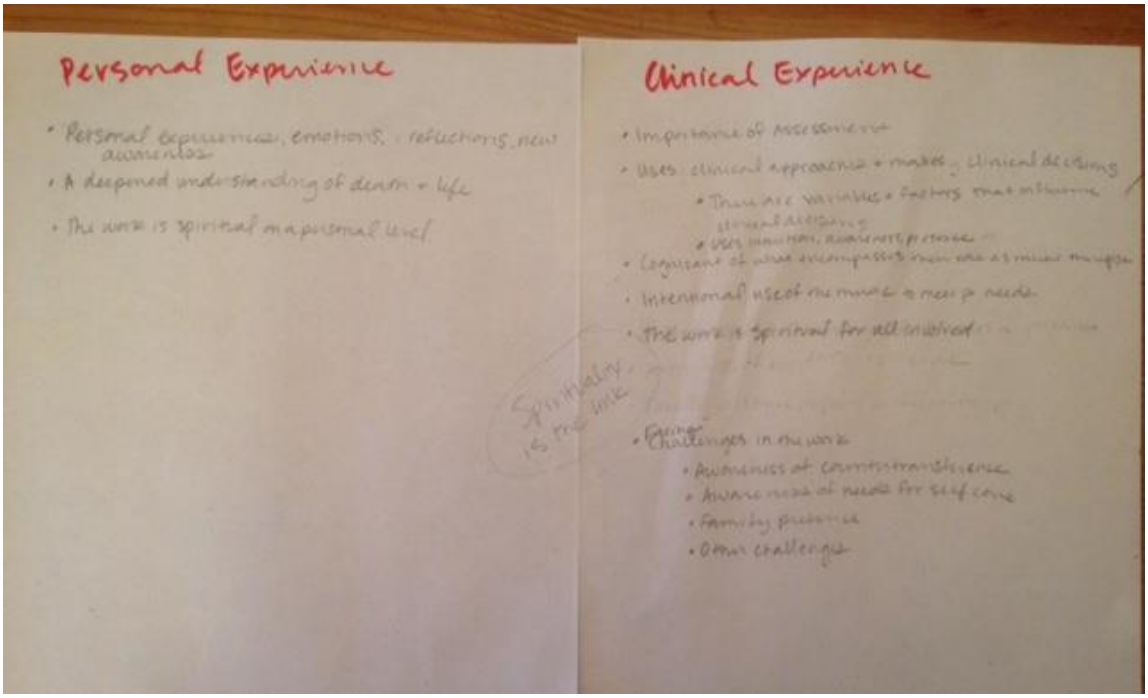
Picture 8: The two themes

Table 1

BARBARA	PHYLLIS	TOVA
Feelings about the work	Feelings about the work	Feelings about the work
Role as music therapist	Role as music therapist	Role as music therapist
Variables/factors	Variables/factors	Variables/factors
Countertransference	Countertransference	Countertransference
Presence	Presence	*Presence*
Approach and clinical decisions	Approach and clinical decisions	Approach and clinical decision
Music (considerations and effects of)	Music (interventions and effects of)	*Music (role, effects of, considerations,*
Assessment	Assessment	*metaphors)*
Personal time for reflection		Assessment
Patients (background)	Personal time for reflection	*Personal time for reflection*
New awareness from the work	Patients (symptoms)	Patients (symptoms)
Personal experience and		**New awareness form the work**
feelings	*Personal experience and*	*Personal experience and feelings*
Intuition	*feelings*	
Challenges	Intuition	*Intuition and awareness*
Working with family	Challenges	Challenges
Work as spiritual	Working with family	Working with family
Self-care	**Work as spiritual**	Spiritual realm
Understanding of death	**Self-care**	Self-care, humor
	Understanding of death	*Understanding of death*
	Therapeutic process	*Therapeutic process*
		Reflected on what it was like to share
		during the interview
		Interdisciplinary team
		Being present at time of death

Table 1: Preliminary themes for each participant

I then outlined the sub-themes from this array of groupings.



Picture 9: Rough draft of themes and sub-themes

Noting that spirituality was shared between the two groups I wrote “spirituality is the link” across both pages. As I sorted through the participants’ quotations it became clear that countertransference, particularly in regard to emotions, was experienced in both personal and clinical realms.

Chapter 4: Results

The results of my analysis revealed that music therapists have clinical experiences and personal experiences when working with actively dying hospice patients, and spirituality and emotions are experienced both clinically and personally. Clinically, these experiences include (1) Use of ongoing assessment; (2) Clinical reasoning, (2a) Clinical approaches, (2b) Variables and factors that influence clinical decisions, (2c) Use of intuition, (3) Importance of and presence; (4) Clinical use of music to meet patient needs; (5) Roles as music therapist; (6) Facing challenges in the work; (7) Awareness of countertransference, (8) Family presence and influence; and (9) Working with patients' spirituality. Personally, these experiences include (1) Awareness of needs for self-care; (2) Emotions and new awareness from the work; (3) A deepened understanding of death; and (4) The work as spiritual on a personal level. See Table 2 below.

Table 2

THE MUSIC THERAPIST'S EXPERIENCE WHEN WORKING WITH ACTIVELY DYING HOSPICE PATIENTS		
Clinical Experiences		**Personal Experiences**
1. Use of ongoing assessment 2. Clinical reasoning a. Clinical approaches b. Variables and factors that influence clinical decisions c. Use of intuition 3. Importance of presence 4. Clinical use of the music to meet patient needs 5. Roles as music therapist 6. Awareness of countertransference 7. Family presence and influence 8. Working with patients' spirituality	S E P M I O R T I I T O U N A A L L	1. Awareness of needs for self-care 2. Emotions and new awareness from the work 3. A deepened understanding of death 4. The work is spiritual on a personal level

Table 2: Final analysis of themes

As depicted in the table, the participants appear to have clinical experiences in their professional role and personal experiences that include their own emotions, understandings, and perspectives. The middle column represents the incidence of spiritual and emotional aspects in both the clinical and personal experiences. The lines at the bottom of the column have been removed to show the shared space between the

two types of experiences. The two main themes of clinical experiences and personal experiences and their sub-themes are explained and clarified below.

Clinical Experiences

1. Use of ongoing assessment

Barbara, Phyllis, and Tova each spoke to the importance of ongoing assessment when working with actively dying patients. They noted that they observe the patient very closely for any signs that would serve as information to help them provide music that would be supportive and promote comfort. Typically the patient is unable to respond, so they look for physical signs of comfort and discomfort. Assessment of the patient occurs the entire time they are with the patient, and they adjust their approach accordingly at any given moment. The participants described physical signs, and in particular breathing, as important in their assessment of actively dying patients. Barbara mentioned how she uses the music as part of assessment to help notice signs of changes in breathing.

> Phyllis: [I observe] definitely breathing, definitely what their face is doing, what I see eyebrow movements, facial movements, if they're conscious they can be agitated or whatnot, so start looking for a goal, what's my purpose here, what's my goal? And that's such an in-the-moment process, rather than one you can plan…I think just paying attention is so important, paying close attention.

> Barbara: One of the things that I sometimes say, joke, that I watch the person's chest more than their face. I mean I'm watching their face too, but to match

their breathing, to match where they are, if, especially toward the end sometimes the breathing's erratic, and that's another thing I'm watching for, you know the final breath, sometimes you can really tell through the music.

Tova: My best guess is that that breath is present for them, you know what I mean because it's so intense, their chest is moving because it just feels like, insofar as they're aware of anything that breath might be it, right? So it would make sense for me, inasmuch as I can imagine what they might be experiencing of themselves dying, to me, that the music would *join* that, would *accompany* that breath.

Phyllis noted that knowing the patient's spiritual and cultural background are essential to the provision of music, as well as her general sense of what is happening in the moment:

Phyllis: I think with an actively dying person, knowing their spiritual background is really important…a lot of very southern people, they need their gospel songs, I mean it's just their language! … How I play them, again, really depends on the feelings in the room, also on my goal, what needs to happen in the moment.

Tova's assessment includes looking for signs of distress caused by the music. Because the patient cannot verbally respond she is very careful about not causing harm.

Tova: It's like, observing in as many ways as you can, but without having any sense of anybody giving anything back, or necessarily plugging into the fact that I'm there…I think part of the observation is about, just wanting to make very

sure that I can't see any signs of causing distress. And for me mostly that comes right here, this spot right between the eyes (Tova pointed to her forehead, where wrinkles would happen when grimacing).

2. Clinical reasoning

Clinical reasoning is the process by which music therapists consider all information available to them in order to make clinical decisions (University of Newcastle, 2009). The participants discussed factors of clinical approaches, variables, and use of intuition and presence.

2a. Clinical approaches.

Each participant described how they approach actively dying hospice patients. Phyllis described her approach as non-directive:

> Phyllis: So, obviously meeting them where they are, starting where they are, is important I think. And then just, following them in whatever, wherever they need to go.

Barbara described her approach as patient-centered:

> Barbara: It's all about them. It's not about me at all. It's kinda like I'm the vessel to provide that for them.

Tova said she approaches patients with a sense of curiosity:

> Tova: I think at the base of it is this just really intense curiosity. I'm really curious of what somebody's experience is.

2b. Variables and factors that influence clinical decisions.

In addition to the participants' approaches there were variables and factors that also guide their clinical decisions. Barbara noted that the length of time knowing the patient before they went into the dying process has influenced her clinical decisions:

> Barbara: This was a case where I had seen the patient numerous times so I knew what her preferences were and I knew how she responded when she was able to, to the music, so I was able to talk to the family about that and they were open to me playing…

Phyllis described an experience with a patient where she considered knowledge of the patient's religious background to provide music:

> Phyllis: Because I know that's his background, that's his beliefs. So I just played song after song about heaven, observing him, playing along with his moaning or his breathing, but with the songs, and he just calmed.

A factor that influences Tova's clinical decisions is presence of the family. When family is not present she focuses solely on the patient, observing closely and providing music to connect with the patient and promote comfort. However, when family is present more questions come to mind that influence her clinical decisions. Family presence was also identified as a for the participants to work with.

> Tova: If the family [is there], I start to wonder what's going on with them, and I start to go, do they want me to stop? Is this ok? Do they want something

different? Then it becomes this interesting dance with who is this music for? Is this equally for the patient and family, is it mostly for the family?

2c. Use of intuition.

Clinically, the participants indicated intuition as a source of information within their approach and provision of music therapy services. Phyllis spoke of her intuitive sense combined with her knowledge of the patient's religious background as influencing her clinical decisions:

> Phyllis: I had a patient who was very religious…Baptist…So he was moaning so much, and I, I just felt like I needed to play songs about heaven, and I wouldn't normally choose that on my own, but I just, my intuitive sense was that he needed that, and he needed that comfort.

Phyllis also talked about choosing "just the right songs" based on her intuition:

> Phyllis: And sometimes that will lead me to just picking, like with the family's there, and I just choose something, and they'll go "that's their favorite song!" and they weep like it's something that I've…for some reason it has happened a lot to me.

Tova spoke of her intuitive sense as a sensory experience:

> Tova: I feel like it's like this super sensory opening process that happens where I feel like I'm, I go into a, a sensory place really, where I feel like I'm listening and or experiencing everything in the room out of all side of me, it's not just out of

my face and ears and eyes, it's, I don't know, it feels like a very open kind of taking in.

3. Importance of presence.

Presence refers to the demeanor of the therapist in his or her interaction with clients (Schneider & Krug, 2010). Phyllis described the importance of presence within her approach and clinical decisions:

> Phyllis: I think that it's just so important for the music therapist to be that strong presence though, to be that grounding, create that grounding space…I think it's so crucial to be like just *so present* with them and following them really well, but then pushing it, pushing it slower, or just pushing it more soothing and less rhythmic or something like that, you know?

Barbara spoke to the importance of presence and she noted when it is challenging to be present.

> Barbara: That I need to be the strong person for them and that I am there kind of as visitor, not to invade, not to take over, but to just be that support and that I need to remain calm and let them guide the way…I do get sometimes with patients if they're not real responsive I'll find myself, my mind wandering. I guess that's pretty normal, but usually I'm able to bring it back and say "This is what I'm here for."

4. Clinical uses of music to meet patient needs.

The participants noted specific roles and purposes of the music, including examples of interventions, observed effects, and clinical considerations. Phyllis discussed symptom management and shared what she thinks about as far as the elements of music to meet patient needs:

> Phyllis: What's the tempo that needs to happen? What's the rhythm that needs to happen? And what song feels that way?

> Phyllis: Just as far as meeting their breath, and using entrainment is just so helpful, with people who are anxious or agitated.

Barbara spoke of the calming effects of the music:

> Barbara: To use the music and see someone go from angst to calm, and you know, to know that the music has that power.

The participants often talked about indications for using familiar songs, unfamiliar songs, and improvised music. Barbara noted that one thing she considers when using familiar songs are the words, and Phyllis and Tova described their thoughts on using familiar or unfamiliar music:

> Barbara: Thinking about the words. Ideally I have met with the patient or family so I know what music is meaningful.

> Phyllis: Sometimes it's a familiar song will help, and sometimes it's really not helpful, because it's waking them up more, where you want to kind of help them

get sleepier, so sometimes things that they're not familiar with are more helpful, or improvisation.

Tova: I always wonder if just for some people all that familiarity is just like a tether, and for some, definitely hymns are very comforting.

Tova talked when providing music with a less detectable pulse and rhythm is indicated, and what has influenced her thinking on this:

Tova: You can sometimes read accounts of people who've had near death experiences and they talk about sound sometimes, and it's usually a remarkable, they remark on the fact that there is no rhythmic, that it's not rhythmically oriented, that it's sound, but not rhythm, which makes total sense to me, because rhythm is about life and life moving forward, and it's motion, and the kind of motion that they're in is very swirly to me…And so there's a way that I'm trying to do that with my music….

After the music making portion of the interview Barbara talked about how certain instruments, and use of timbre, can be effective in reducing symptoms. Playing a Native American flute brought memories of a male patient who was in a great deal of pain from stomach cancer:

Barbara: I pulled this out and played it for about fifteen minutes…and he was just calm and his pain had decreased significantly.

5. Roles as a music therapist

Each person identified several roles they identify with as a music therapist when working with actively dying hospice patients. Within their role as the music therapist on the hospice team, they described qualities they offer to patients and their families. Barbara spoke of several roles throughout her interview, which include that of comforter, a source of strength, a source of support, and a vessel/provider. Phyllis spoke of her role as being there to provide support to the patients and families. Tova indicated her role as being an "active and participatory witness," as well as one who can provide information and reassurance. She also spoke of her role as a comforting and grounding presence:

> Tova: I think my basic idea is to try and help people feel like…comforted? Or like there is comfort available I guess? Like there is, sort of humanity available. Like there's something beautiful and aesthetic and human here. That there's a presence with them that has no problem with the fact that they're dying. So, I get to be the one in the room that doesn't think this is a tragedy. That doesn't see anything wrong with what's going on. That's just like, totally believing that just like the millions of people that have made it through to death in this world before this person they will also make it through just fine…
>
> Tova: And so they're so freaked out and "what happens when they actually die?" And I can talk about it, and I can really talk about it, and I'm not freaked out and that's comforting to them.

6. Awareness of countertransference

Each participant described challenging situations and issues that have arisen in their work with actively dying hospice patients. These include awareness of countertransference, awareness of needs for self-care, and family presence.

Each participant discussed countertransference, identifying it as a challenge to identify and address those countertransferences in a way that benefits the patient. Sometimes this meant totally bracketing the countertransference and sometimes it became useful information to be used in the music therapist's approach and in clinical decisions. Barbara spoke to the use of bracketing:

> Barbara: Sometimes depending on my relationship with the patient I have to compartmentalize my emotions and push my own thoughts aside so I can be fully present for the patient and family.

Phyllis identified some of her countertransference as a "trigger" and something to recognize as either being most appropriately addressed in personal therapy, or as a source of information about the patient:

> Phyllis: If I'm feeling a lot of my own emotions, I'm noticing that's a trigger for me, and I think as we work we get to know our triggers better and better, and know how to work with that trigger. Because there's nothing wrong with that, it may mean that I'm really, I have a sense of what they're feeling if it's in me too. But if my own feelings are coming up a lot then that means I need to go do some work afterwards, as far as what this is and what I need to do with it…it can be

very unhelpful, but it can be very helpful too…in fact it can actually be some information about what's going on there, but you have to, it's a fine line.

Phyllis described clinical experiences when using her own emotions was helpful in choosing songs:

> Phyllis: I think there are some songs that I know so well, and that I've used in so many different spaces that I kinda know what they might do, so I can more feel them than think of them. It's like "this is a 'What a Wonderful World' kind of moment," right?

Barbara shared how her personal life experiences have manifested in countertransference and how she needed to be aware of how her reactions influenced her approach, as well as how her experiences have left her with a deepened understanding of what families are going through when receiving hospice services:

> Barbara: I think the hardest, my dad died two and half years ago…I had to be very careful not to project my emotions onto whatever situation I was walking into. Basically I put dad in this little compartment up here… But it just felt like that helped me be more empathetic and understand that this is a family member, this is somebody's parent, spouse, and just to think how would I want somebody treating my parent in this situation? That really put it on the front of how to approach these families and know that I have felt that grief that they are feeling.

Tova talked about factors that cause countertransference to emerge or not:

Tova: I don't get a lot of countertransference around, I don't know, around the person dying it seems like, yeah, it's exactly where this person, what this person needs to be doing. It feels pretty clear to me…then the spectrum starts to get much muddier, as I move into people I know better, people who are younger, people who have been active for a really long time, where you like, my God, like, come on, *go*! And if the family's there and they're really broken up, they're really sobbing, then it gets hard not to kind of take that in.

7. Family presence and influence

Each participant shared that they made adjustments to their approaches when family members were present, and family presence was both a factor that the music therapists take into consideration and a challenge in the work. Because family presence was talked about a fair amount it was added to this section as its own sub-theme. Phyllis described how music therapy helps the family:

Phyllis: A lot of times it's about the family if they're there. Sometimes it's about just helping them to feel like they have something to do, or that they can be present with that person cause I think it can just be awkward for them sometimes, they're just sitting there, it helps them to connect with that person and have something to do, to reach them, or to feel like they're helping in some way too. Sometimes it's about helping them express what they need to express to that person, you know, very gently.

Some families have complex dynamics and the music therapist is challenged in managing these situations. Barbara talked about a family of four siblings who were present with their mother who was actively dying. Barbara said "one of the daughters…her grief was the anger type" and there seemed to be a fair amount of tension in the room. She told the family about their mother's previous responses to music and asked if she could play her favorite music. The family agreed and Barbara said the music "kind of diffused the situation for that time." During the music the daughter's anger dissipated and she was able to grieve with her siblings.

Tova's additional clinical questioning when families are present was shared earlier under "2b. Variables and factors that influence clinical decisions." She also said:

> Tova: If the family's there and they're anxious or they're really like, they weren't able to be clear with me before I started playing, what they wanted, and so I'm feeling a need to stop and check in and maybe start playing some more. Those are much harder for me, to just tune in and stay.

In other words, it is sometimes more difficult for Tova to attend to the patient when the family is present.

The most difficult situations for Tova were dealing with family members who requested she play religious songs when she knew for certain those types of songs opposed with the patient's religious and/or spiritual beliefs. She was adamant about respecting the dying person's beliefs and wishes.

> Tova: I think, sometimes I feel conflicted, if the family's asking me to do particular hymns and stuff…but the patient I have had interactions with they were very clear they did not want anything religious, and to have the chaplain tell me "well it's about the family now" and I'm like ooh conflict right? No, the person is still here. Once the person is gone I will sing any hymns you want me to sing. When the person is dead no problem. Active? No, I'll take you next door to the chapel and sing hymns for you. I'm not doing it.

8. Working with patients' spirituality

The participants all noted that the patient's religious and spiritual background is very important to the provision of music therapy. Phyllis' consideration of a patient's religious background in providing music was shown above where she played songs about heaven for a patient. Familiar hymns or other types of meaningful songs might be played, and the primary clinical goal may be of spiritual nature.

> Barbara: But some of the goals are just to keep them in the sacred space, to help them get there and stay in the calm space and not to pull them out of it…and one of our interventions we have on our care plans is "a creation of sacred space."

Clinically, Barbara was aware of her patients' needs for spiritual support. She described "sacred space" as a meaningful connection with the patient where the patient appears to be experiencing peace.

Personal Experiences

1. Awareness of needs for self-care

Each participant spoke of self-care as mandatory. Phyllis talked about identifying feelings or thoughts that get in the way of working with a patient and needing to "go and do some work afterwards," meaning personal processing or seeking therapy. Barbara reflected on how she uses music for self-care:

> Barbara: And I love to play and, whether I'm with patients or not, it's a good way to just internalize, or let what's internal to come out.

The participants each talked about actions for self-care taken before and after visits. Each reported taking time to prepare before the visit, and taking time to process after the visit. Barbara described her experiences:

> Barbara: I listen to podcasts a lot cause I drive so much, and I just turn it off and have the silence there just kinda get myself ready for it so that I will be a calm presence when I enter the room. Just some deep breathing, and prayer…
>
> Barbara: I just go in silence and just kind of de-brief myself and reflect on the visit…there are places to pull off to see the scenery and I have pulled off before and just sat there and taken that in.

Phyllis also talked about her before-and-after actions of self-care:

Phyllis: If I walk into a nursing home or something I definitely feel my feet on the ground and just be present with, remind myself to be present. Sometimes I need to stand outside for a minute and take a breath.

Phyllis: I think sometimes you know, we need that [processing afterward] and sometimes we don't. Sometimes I needed to not see another person, not to go see my next person if it felt like I needed to pull a short break. Sometimes taking a walk…sometimes I have to cry, and sometimes I'm good, good to go!

Tova described avenues of self-care taken after working with actively dying hospice patients to regain a sense of balance:

Tova: There's a need in the next while to just absolutely know I'm among the living (laughs), like I need to hug people and reinvest in being here, like this is my time here…I might go outside and, and really walk, or just super snuggle my kids, if I can see my partner that would be great…I might play, I have a couple pieces I really like to play sometimes….I mean I think the experiences there's such a sense of awe, and, an honor, and sort of humbleness that comes with being there, and then there's some kind of balance for me that needs to happen, like sometimes I'll get raucous!

Tova also spoke to the importance of humor in staying balanced and healthy:

Tova: If the chaplain or, the social worker are there who I know really well, we kind of do that for each other, you know we tell jokes. [She shared a story of a

joke told by a nurse.] …I think I laughed until the tears rolled down, because I think it was just so, it was just a release.

2. Emotions and new awareness from the work

Emotions felt during hospice visits with actively dying patients were discussed. These emotions can be considered within the realm of countertransference however they did not seem to be activated by the music therapist's past or current life situation; instead, they seemed to be primordial in nature and actuated from the authentic human interaction with the dying person, and sometimes the family. In addition, these emotions seemed more personal to the music therapist and the meaning they found in their own lives. Phyllis recalled working with a couple whose love story was quite poignant, and Tova said that she was moved to tears when present at the death of patient.

Phyllis: Or, you know that person's love story is just too much and I can't take it! I probably could have wept for them that day.

Tova: I'll often have to stop vocalizing at that point because I get so, I got so, in the two that come to mind, where I was so choked up, there was no way, I mean I was probably crying, not sobbing-sobbing but tears, um, and I can't sing while I'm crying, it's just not possible.

Tova also said she feels compassion toward her patients and families:

Tova: I have a ton of compassion for people who in the journey not of their own volition thank you very much. I'm choosing to be here, and almost nobody else is choosing to be here.

After making music with her Native American flute Barbara shared how a memory of a patient was with her as she played. She remarked how she feels especially close with some patients, and experiences with them in the music have touched her.

Barbara: Some patients just kind of stand out in your mind. It's usually the ones that you've spent the most time with or had the longest. But he was a very unique person.

It was also only after the music Tova more deeply reflected on what it is like for her to leave the dying person and re-enter her life.

Tova: When I stopped playing the Reverie Harp it was really a lot of my experience after I stopped, after I stop being with a person who is actively dying, like it was kind of my coming back to, there's something about looking at the word Reverie in there, and it was just like oh that's a celebratory come back to life word to me, like revitalize, re-engage and re-invigorate.

Barbara also described how her experiences have shaped new awareness and perspectives on life:

Barbara: I have such a diverse culture that I work with…when they get to the point of dying they're in the same place, it doesn't matter. I don't know how to

put this, it gives me a lot of perspective on end of life, is that you don't need all this stuff….it gives life a lot of perspective, especially if things aren't going well.

3. A deepened understanding of death

This theme most prominently emerged for all the participants after the mandala drawing and music making portions of the interview. I used the participant's descriptions of the mandalas and my observations of their music as evidence toward this theme, as well as their words about their deepened understanding of death. Their words about this theme are sparser compared to their descriptions of their clinical experiences, as their understandings of death mostly emerged in the verbal reflections after their drawings and music.

Mandalas.

Barbara described the lines of her mandala as the hospice patients she has worked with. They begin with a full life at the top and the motion is downward, representing the life span. The lives "trail off" and the patients die. The darkness the lines have trailed off into is the space the spirit goes after death. *Barbara drew her understanding of death.* See Picture 3.

Phyllis drew spirit within the orb, with the blue encircling the orb and holding it together, connecting all of us as spiritual beings. The blue allows the spirit to exit at the top. This is the spirit exiting the body. *Phyllis drew her understanding of death.* See Picture 4.

Tova's mandala shows a spiky maroon border, which she identified as her presence as a human. She said it includes her energy as well as her music, and it is warm and loving. It is holding the life of the patient, which is the yellow spiral. The dying patient's energy is swirling and moving upward, finally exiting the top as the person dies. The energy continues and dissipates. *Tova drew her understanding of death.* See Picture 5.

> Tova: It just goes and trails off. So there's a way that this is the boundary of life. So like the whole, the whole world of that person's being has come down to just what's inside that circle and then it's just gone.

Music.

The end of each participant's music was a gradual fading to silence, a metaphor for death that was seen in the mandalas as a dissipation out the top of the circle. Phyllis used a jam block that she indicated was a heartbeat:

> Phyllis: …and then I wanted a (makes three clicking sounds with tongue) for some reason (laughs). It felt like maybe it needed some sort of ending, or some sort of like we're coming back to the heartbeat, or something that reminds us that we're here…And that was "sphew" like disperse the energy.

Tova described the last instrument she played also as a release of energy:

> Tova: And these have always sort of reminded me of (plays chimes) spirit without substance, whatever that is…They're *very ethereal*.

4. The work is spiritual on a personal level

As can already be seen in the mandalas and music, the participants have had spiritual experiences when working with actively dying hospice patients. Barbara described her experience:

> Barbara: And I really feel that sacred space, that bond between me and the patient sometimes, and that's just so powerful, it's like, we're connecting on some other level… Very, very spiritual!

Barbara also described her spiritual experiences as an altered state of consciousness:

> Barbara: Sometimes in the moment, you get these, it's almost like, not out of body, but the altered state of consciousness, it's like, something else is taking over to get me through this.

Tova spiritually prepares for work with an actively dying patient by using a meditation mantra:

> Tova: So I'm a meditator I have been for a long time. I have kind of a little meditation mantra that I say as I'm walking into a facility that I work in or house or whatever…. But I actually do it again, specifically before I know I'm going into somebody who's active.

Phyllis and Tova shared their thoughts on spiritual experiences after the mandala drawing and music making. It was as if the modalities for creative expression allowed

the participants to reach deeper levels of understanding and communicating their experiences. Phyllis described her spiritual beliefs within the work:

> Phyllis: I believe that everything has sort of an order, yin and yang, that everything happens for a reason at a certain time, and like all of it is supported, whether we feel grounded or whether we're letting ourselves get into this misty stuff, this spiritual stuff that we're all, all of it is connected, we are all connected…

Tova reflected on the spiritual nature of her work both in and outside her work:

> Tova: What is the animating presence? What is the animating presence that blazes through me that's not there anymore? And if it's not there anymore, does it just vanish? I love that we don't know. I love that we don't know. It's so great. (Erin: It's the greatest mystery) Tova: It is.

Chapter 5: Discussion

In this research study I explored the experiences of hospice music therapists when working with actively hospice patients. My initial research questions were (1) What do music therapists experience when working with actively dying hospice patients?, and (2) How do music therapists prepare for these visits, and then process their experiences afterward? The first question was answered by the emergence of the two main themes: clinical experiences and personal experiences, and corresponding sub-themes. The second question was answered within the theme of personal experience and sub-theme of awareness of needs for self-care.

Hospice music therapists bear witness to life's greatest mystery: death. Because of the profound nature of this work, and my own difficulties expressing my experiences as a hospice music therapist, I included creative modalities of mandalas and music making in hopes that more information would emerge that would not otherwise in a strictly verbal conversation. The mandalas and music did indeed serve as means to further discussion and materialization of new information, notably that the participants experienced a deepened understanding of death. In this chapter the function of the mandalas and music are discussed, the shared themes of spiritual and emotional experiences are discussed, and the remaining themes and their significance are discussed.

Function of the Mandalas and Music

Recent advances in arts-based research promotes the use of creative modalities to explore research questions (Viega, 2016; Viega & Forinash, 2016). Art plays important roles in research and leads to new or deepened understandings (Aigen, 2010). The mandalas and music in this study functioned as adjunctive means in data collection, which resulted in more information that was included in the data analysis. While the participants mostly discussed their clinical experiences in the first part of the interview, it was only during and after the mandala and music making that deeper levels of their experiences working with actively dying patients were uncovered. The experience of drawing and making music within the interview might have helped the participants more closely connect to their experiences, thus resulting in additional data collected around their experiences.

New material that had not been shared prior to the mandalas and music included (a) understanding of death, (b) self-care, (c) work as spiritual, and (d) new awareness of the work. Further information around already-discussed topics also emerged and these included (a) new awareness of the work, (b) music (considerations and effects of, role, metaphors), (c) personal experience and feelings, (d) personal time for reflection, (e) personal experience and feelings, (f) intuition and awareness, (g) understanding of death, and (h) therapeutic process. The experience of making art and music seemed to make connections that were more personal in nature. For example, the act of making music in the interview reminded Barbara how important her own music was to her self-care. See Tables 3 and 4.

Table 3

BARBARA	PHYLLIS	TOVA
Understanding of death	Work as spiritual Self-care Understanding of death	New awareness from the work

Table 3: New preliminary themes from participants' thoughts after the mandalas and music

Table 4

BARBARA	PHYLLIS	TOVA
Feelings about the work Music (considerations and effects of)	Personal experience and feelings	Music (role, effects of, considerations, metaphors) Personal time for reflection Personal experiences and feelings Intuition and awareness Understanding of death Therapeutic process

Table 4: Preliminary themes discussed more after the mandalas and music

What stood out to me after the interviews was noticing that the mandalas depicted each participants' understanding of death. As was stated in the method section, I did not ask them to draw their understanding of death specifically, and I provided an open directive to "continue your reflection of working with actively dying hospice patients as you choose colors to come onto the paper." What is also remarkable is that their mandalas have similar qualities, such as all on black paper with a rounded, upward-shaped movement ending in dissipation of the colors. The mandalas lead to more questions, such as do these qualities reflect a shared cultural understanding of death?

The participants' music also had similar qualities compared to one another. They each had clear beginnings, middles, and ending sections. The beginnings were loose, rhythmic (and in Tova's case melodic) explorations of sound before moving into fuller, more active expressions. Each ended their music with a gradual fade into silence. Phyllis and Tova described their music as a dissolution of energy, indicating that their music was an expression of death that reflected their patients' transition from life into post-life.

As stated earlier, the participants spoke a good deal to their clinical experiences, which makes sense because they are functioning in a professional role on the hospice team. However, working with people who are dying is a profound human experience for the music therapist. Two possible reasons for that disconnect with their personal experiences are (1) their focus on their clinical role and (2) limited opportunities to talk about the personal side of their work. In fact, Tova remarked several times in her

interview, “it’s funny, I’ve never talked about this.” The modalities of creative expression helped further uncover these personal experiences.

Increased awareness of personal feelings and their impact on clinical work is an important responsibility of the music therapist (AMTA, 2014). Hospice music therapists may be well-served by supervision from a seasoned professional in order to come into a deeper understanding of the intersections between clinical and personal facets of the work (Wilkerson, DiMaio, & Sato, 2015). Supervision appears to be underutilized by hospice music therapists, however, with only one third of respondents reporting they have received supervision in a study done by Jackson (2008). Wilkerson et al. (2015) encourage hospice music therapists to seek supervision and promote it as one of the most effective ways of developing self-awareness, processing personal feelings, and integrating those to clinical practice. In fact, Forinash and Gonzalez’s (1989) study emphasized clinical observations and personal experiences as influential in the provision of music therapy. Given the utility of the mandalas and music improvisation in this study, creative modalities within supervision may be effective in increasing awareness of personal experiences, as well as countertransference, which results in greater ability to provide highest quality service to patients and their families.

Spirituality and Emotions

Spiritual and emotional experiences were found as shared between clinical experiences and personal experiences. Clinically, the participants worked with the patient’s religious and spiritual beliefs, and personally, the music therapists had spiritual

experiences. In the same vein, emotions were experienced as countertransference that impacted clinical decisions, as well as provided meaningful personal experiences for them. Sometimes these spiritual and emotional experiences felt shared, as in the case of Barbara who said "it's just so powerful, it's like, we're connecting on some other level." Overall, the tone of the participants' words, drawings, and music was that working with actively dying hospice patients is a meaningful experience.

This study found that spiritual needs were addressed with actively dying hospice patients. The literature has shown this also, as in the case of Wlodarczyk's (2007) study which affirms music therapy's role and effect on spirituality of hospice patients, Hilliard and Justice's (2011) case where songs supported a patient's spiritual beliefs, and Hong's (2016) literature review. The participants in this study discussed similar spiritual themes of patients that were found by Magill (2005), such as faith, meaning and purpose, and peace. Of note, Phyllis' description of her work with a man of Baptist faith who was agitated, and her provision of songs about heaven brought him to a place of peace and relaxation.

Music therapists' accounts of personal spiritual experiences have also been discussed in the literature. In the first phenomenological study of its kind, Forinash and Gonzalez (1989) describe images they experienced during a session with an actively dying hospice patient, which included feeling/seeing the client reach her hands toward God. In a related study Marom (2004) conceptualized the music therapist's spiritual experiences as witnessing the client's spiritual experience, sharing a spiritual experience with the client, or having a personal spiritual experience. There is agreement between

the present study and Marom's study in that music therapists have spiritual experiences that lie in both clinical and personal domains.

The participants in this study identified emotions as countertransference in their clinical work. In defining countertransference I took a "totalist" perspective while analyzing the data, and this view has been discussed by Wilkerson et al. (2015) in an article that covers countertransference at end-of-life. They posit that all feelings and reactions within the music therapist are countertransference, and the music therapist should aim for self-awareness in order to best support the patient. Working in hospice can tap into the music therapist's beliefs, fears, grief, and anxieties, and the music therapist may step into a "role" and play out a past relationship.

Participants in this study said it was important to recognize what to do with their feelings, such as whether to set them aside or to use them in the therapeutic process. Barbara talked about the importance of bracketing the feelings she had around her father's death, and Phyllis noted countertransference to sometimes be useful information. She explained that it can provide insight into how the patient or family member is feeling, which in turn informs the music therapist's clinical decisions. These lines of thinking are validated by another source of literature. Potvin (2015) described his process of examining his countertransference and noting where his life experiences overlapped and how that was shaping his approach.

The participants also reported personal emotional experiences that impacted them in meaningful ways. This type of countertransference was also found by Dorris

(2015), and this emerged as a central theme to her study. Similar to the present study she found that countertransference is deeply influential in the clinical process and the music therapist's personal life. A sub-theme of her study states "countertransference influenced personal and spiritual revelations." Emotions and new awareness from the work was discussed by the participants, mostly in the verbal parts of the interviews, and with a bit more information after the mandalas and music making from all the participants. For example, Phyllis shared a time when she was deeply moved by the love story of a patient and their spouse, and Tova was moved to tears when present at a death and witnessing the raw grief experienced by the family. Also, Barbara spoke to her work with actively dying patients as shifting her perspective on life with a deepened understanding what is truly important.

Clinical Experiences

Awareness of countertransference and working with patients' spirituality was discussed above. The remaining themes of use of ongoing assessment, clinical reasoning, clinical use of music to meet patient needs, roles as a music therapist, and the challenge of working with families are discussed below.

The participants spoke extensively on their clinical experiences. They reported experiences of ongoing assessment throughout their visits with actively dying hospice patients. This theme is shared with Dorris' (2015) study, and one of the primary themes she found was also ongoing assessment, with subthemes of the importance of knowing the client's background, and assessment of physical state can help determine the

patient's internal state (particularly breathing). The participants in the present study also noted that because the patient is non-responsive most of the time they try to obtain information from others about the client's background, including religious/spiritual information and preferred/familiar music. The participants in this study also said they observe breathing as a primary indicator of the patient's condition, which was also found as a primary theme by Forinash and Gonzalez (1989) and discussed by the participants in Dorris' (2015) study.

Components of clinical reasoning that were found were clinical approaches, variables and factors that influence clinical decisions, and use of intuition. Clinical approaches in hospice music therapy have been described by Hilliard (2005) as a mix of cognitive behavioral and humanistic orientation, and DiMaio (2010) as humanistic. At the beginning of the interview the participants described their theoretical approaches, and then within the interview described their approaches informally as "non-directive," "patient-centered," and "curiosity-driven." Factors that influence clinical decisions were found to be length of time knowing a patient, the goal of the session, and family presence, and these align with Mandel's (1993) discussion of the role of the music therapist. Descriptions of these types of considerations have been (though rarely) discussed as part of the process within case examples in the literature; for example, in DiMaio's (2010) descriptions of using Music Therapy Entrainment with hospice patients.

Another similarity to Dorris' (2015) study is use of intuition as an important role in the music therapist's approach. Intuition was included within the theme of Clinical Reasoning in this study. Brescia (2005) qualitatively explored the music therapist's

experience of intuition and found that it involves physical messages, emotional messages, auditory messages, and visual messages. In this study the participants described their intuition as a "knowing" or a "sense" of the patient or situation. Phyllis described her intuitive sense with an actively dying patient, and taking into consideration his spiritual background, she had a sense of "knowing" that songs about heaven would be comforting. Phyllis also noted that she had a knack for choosing "just the right songs" as indicated by the family. Tova described her experience of intuition as a taking in information from all of her senses.

The importance of presence was another finding in this study that is supported by the literature. Muller's (2008) phenomenological investigation of music therapists' experiences of presence revealed that both intention and openness to the as-yet-unknown are involved in being fully present with clients. Along these lines, the participants in this study noted that it is of utmost importance to be fully present to dying patients in order to support their needs. As Phyllis said, "I think it's so crucial to be like just *so present* with them and following them really well."

In regards to family presence, Dorris' (2015) study revealed a theme about family presence and the music therapist collaborating with them to help the patient have a peaceful transition, and in this study all participants noted that their clinical approach shifts to include the family when they are present. Interestingly, family presence was also noted as a challenge by two out of three participants, which is in contrast to Dorris' findings.

The literature abounds with studies and discussion of clinical uses of music to meet patient needs. Quantitative studies have verified music therapy's effectiveness for a number of symptoms (Clements-Cortés, 2011; Gallagher et. al, 2006; Hilliard, 2003; Horne-Thompson & Grocke, 2007; Krout, 2001; Whitall, 1989; Wlodarczyk, 2007) and case examples have described music therapy interventions and client responses (Aldridge, 1999; Bruscia, 1991; Bruscia, 2012; Dileo & Loewy, 2005, DiMaio, 2010, Meadows, 2011). The patients involved in these studies were stable and not actively dying. The participants in this study described interventions from the literature such as receptive experiences, attendance to breathing, and relaxation experiences in their descriptions of effective uses of music. The participants' uses of music also align with West's (1994) descriptions of the use of music with the dying, such as using improvisation and attention to the music elements to support the dying process.

Barbara, Phyllis, and Tova each spoke to what they think and feel are their roles as the music therapist. Words such as "it's an honor," and "active and participatory witness" were shared. Potvin (2015) described his role as the music therapist attending to an actively dying patient and her family. He described the process as a narrative with each person having a role and he supported them and their shifting roles and identities in, ultimately, a process of transformation. West (1994) described the music therapist as a witness and a listener, serving as mirror of validation. It is clear that within the overall role of music therapist, the music therapist brings qualities in effort to support that patient and family.

Barbara, Phyllis, and Tova described what it was like for them to also work with families. It is interesting that some of their experiences contrast somewhat with Dorris' (2015) findings, which described family interaction to be a "dynamic process" that is "equally as meaningful" to the family as it is the patient. In the present study Tova expressed family presence affecting her ability to be present, and experienced feelings of conflict when family requested religious music that did not align with the patient's beliefs. Barbara's tone was softer as she described how music can "diffuse" tense family dynamics. Phyllis' perspective more aligned with Dorris' findings in that she uses the music to help the family connect with the dying person, to have something to do, and help them express their thoughts and feeling to their loved one.

Personal Experiences

Emotions and new awareness from the work, a deepened understanding of death, and the work as spiritual on a personal level were discussed above. The remaining themes of awareness of needs for self-care and physical and sensory experiences are discussed below.

Self-care practices were described by the participants, particularly when preparing before and processing after a visit with an actively dying hospice patient. They described ways they prepare before visits by taking time to breathe or pray, as well as taking time after visits to process by being in nature or connecting "with the living" as Tova said. The need for self-care is supported by the research of Scheer (2013), whose

qualitative investigation of self-care by hospice music therapists revealed similar rituals and self-care practices.

Physical and sensory experiences were described by Barbara and Tova. Barbara noted that she sometimes feels the guitar strings with her fingers and really notices the physical sensation. Tova reflected on the physical experience of becoming stiff from sitting in one position for a long time, which seems to indicate her full awareness of and presence toward the patient, thus forgetting about her own body. Aversive sensory experiences, such as bad smells, was also noted by Tova.

Implications for Clinical Practice

The primary reason for a person to receive hospice care is symptom management throughout the course of their illness and decline, and especially during their process of active dying. As a member of the interdisciplinary team, the music therapist offers comfort, support, and symptom management through the dynamic interplay of the therapeutic relationship and music experiences. To be in the presence of a dying person and possibly also their family, is a profound and existential experience for the music therapist. Coupled with providing music to soothe, comfort, and help the person transition another heavy layer of experience is added, and this experience is not easy to describe to others.

The outcomes of this study provide insight into the experiences of the music therapist when working with actively dying hospice patients. The clinical experiences that were described are helpful for hospice music therapists, music therapists in other

settings, disciplines within hospice, other healthcare disciplines, and anyone else interested as to what the practice of music therapy looks like in hospice. It helps others "get into the music therapy mind" of the music therapist. Hospice music therapists may gain a deeper understanding of their own experiences with actively dying patients, and consider creative modalities to gain more self-awareness. Music therapists interested in moving into hospice work might find this information informative as they shift the focus of their practice. Additionally, this information could be shared with other hospice and non-hospice disciplines to help them understand what a music therapist does and experiences, noting the similarities and differences compared to their profession.

Another group who might benefit from this information are music therapy educators and internship supervisors. They may find this useful information to help prepare students for hospice work. The idea of working with a person who is dying may be uncomfortable for students at first, and descriptions from the music therapist's perspective may help bring an understanding of this type of clinical practice. Also, the creative modalities served to deepen the participants' awareness of personal feelings in and from the work, and utilizing creative modalities in the classroom and practicum and internship supervision may be helpful for students to understand how to work with their feelings and recognize the impact of their personal experience on their clinical work.

Limitations and Recommendations

Even though IPA supports an interpretive lens when analyzing the data, my perception of the participants' words presents as a limitation. While I made every

attempt to understand their experiences from their perspectives, I could not help but use my own way of organizing and conceptualizing the data. It is possible that the data could have been organized in a different way by someone else with a different background of life experiences. In addition, more involvement with the participants may have impacted the outcomes as well, such as having one or more follow-up interviews or sending them preliminary results of the data analysis to ask for their feedback. Additional follow up requires more time and effort on the part of the participants, so monetary compensation should be a consideration.

Another limitation was demographic similarities of the participants. All were white adult women with about the same years of experience in hospice (nine to twelve). Two lived in a southern state and one lived in a northeastern state of the United States. While there were differences in religious and spiritual beliefs, they stated similar theoretical frameworks and approaches to hospice care. Increased diversity among participants may reveal different types of experiences.

Topics recommended in future research are shared spiritual and emotional experiences of music therapists and hospice patients and families, interventions and approaches specific to actively dying hospice patients, personal perceptions and awareness influenced by the work, and cultural factors in death and dying. Because it is shown in this study, and indicated in Marom's (2004) study, there are moments when both clients and therapists have spiritual and emotional experiences, and this is worth further inquiry to help music therapists understand how to manage those moments and support the client. Interventions and approaches with actively dying patients are

difficult to research due to the ethical concerns of gaining consent when consciousness is variable. Further qualitative studies around the music therapist's experiences would lend to increased information that would be difficult or unethical to obtain from patients themselves. Because the mandalas and music served to deepen reflection on personal experiences, personal perceptions and awareness influenced by the work could be further explored through arts-based research. It is also recommended this study be replicated with music therapists and hospice patients from other cultures to examine similarities and differences in clinical practice, and to help music therapists develop culturally mindful approaches.

It is highly recommended that music therapy researchers consider creative modalities within qualitative research. Words are limiting. As seen in this study creative modalities of mandalas and music brought forth additional thoughts on previously discussed topics, as well as new information, and this information was reflected verbally and evidenced in the mandalas and music. This study would have looked different had these modalities not been included. Other types of creative modalities could include music composition, music and imagery, dance/movement, sand art, clay, collage, and poetry.

Conclusion

This study explored three experienced music therapists' experiences when working with actively dying hospice patients. The participants shared their experiences verbally, drew mandalas and reflected on them, and improvised music and reflected on

it. The interviews were transcribed and themes emerged through a process guided by Interpretive Phenomenological Analysis.

Clinical experiences and personal experiences were identified, and spirituality and emotions were identified as present in both experiences. Clinically, music therapists' experiences entail the use ongoing assessment, clinical reasoning (clinical approaches, variables and factors, and use of intuition), presence, clinical use of the music to meet patient needs, roles as a music therapist, facing challenges in the work (awareness of countertransference and family presence and influence), and working with the patient's spirituality.

Personally, the music therapists' experiences involve awareness of needs for self-care, physical and sensory experiences, emotions and new awareness from the work, a deepened understanding of death, and the work as spiritual on a person level. The creative expressions within the mandalas and music elicited more information especially around the personal experiences, and it is recommended that future phenomenological, or other types of qualitative research, consider the inclusion of creative expression to help participants access and share a broader and deeper awareness of their experiences.

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